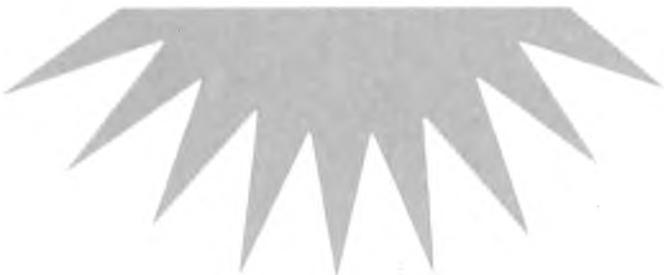




Service Outcomes for Drug- and HIV- Affected Families

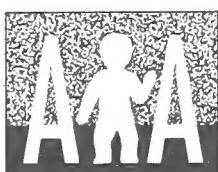


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Service Outcomes for Drug- and HIV-Affected Families

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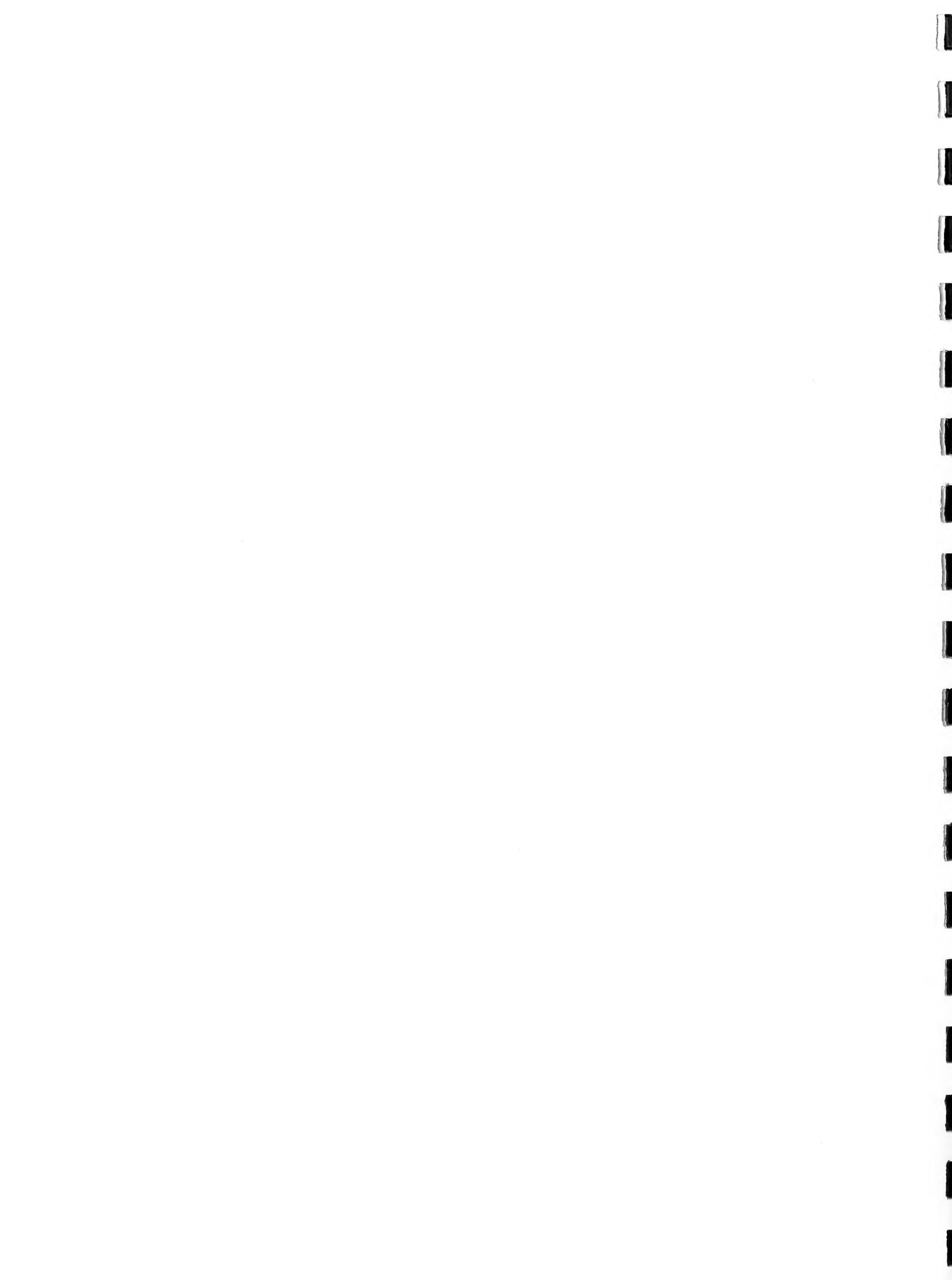
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Introduction

THE NATIONAL ABANDONED INFANTS ASSISTANCE RESOURCE CENTER'S MONOGRAPH ON SERVICE OUTCOMES FOR DRUG- AND HIV-AFFECTED FAMILIES

Sheryl Goldberg, M.S.W., Ph.D., Richard Barth, Ph.D., Megan Vogel-Edwards, M.S.W.

In 1988 Congress enacted the Abandoned Infants Assistance (AIA) Act (P.L. 100-505) to promote protection and permanency for infants at risk of abandonment as a result of parental HIV/AIDS infection and/or substance abuse resulting in the infants exposure to HIV/AIDS and drugs. The AIA Act provided for the development of model service demonstration projects with the focus of: (1) preventing infant/child abandonment through the provision of necessary services to HIV/AIDS-affected and/or drug exposed children and their families; (2) promoting permanency for children through assisting families in staying together or finding appropriate foster care placements; (3) recruiting and training new foster families for abandoned infants and children; (4) recruiting and training health care and social service providers to work with these children and their families, foster families, and residential programs; and (5) providing residential and respite care programs to serve HIV/AIDS and drug-affected children and their families.

In December 1991 Congress reauthorized the AIA Act (P.L. 102-236). The reauthorization mandated service delivery to perinatally drug-affected and HIV-exposed infants and their families, and enlarged the scope of the programs to include the concept of comprehensive service sites. In October 1996, AIA legislation was reauthorized for five years, through fiscal year 2001(P.L. 104-235). The reauthorization made funds available to public and non-profit private agencies and universities to continue the provision of comprehensive programs to address the social service needs of the target population and to provide training and technical assistance to facilitate expedited permanency planning for children.

AIA Programs

The Children's Bureau, within the Administration on Children, Youth, and Families, U.S. Department of Health and Human Services, currently administers funding for 27 AIA demonstration projects and The National AIA Resource Center. AIA programs include a diverse network of service providers. The demonstration projects operate out of hospitals, community-based child and family service agencies, child welfare agencies, and drug and alcohol treatment centers. The goal of AIA programs is to provide assistance to address the service needs of parents/caregivers, infants and children in a streamlined fashion with constructive and coordinated long-term solutions for permanency.

AIA Clients: Families at Risk

Clients who receive services from AIA programs include the abandoned infant or "index child", siblings, the biological mother and/or father at risk for abandoning an infant, foster families, and other caregivers.

Beginning in 1992, programs have reported on clients served and services provided using the AIA Program Summary Statistics Form. AIA programs report that between 1991 through 1995 they served nearly 25,300 children, parents, and caregivers. Because of missing data, the total number of clients served through AIA programs remains undercounted. It is estimated that at least 26,500 individuals have received AIA services since the programs' inception (Goldberg, Barth & Hernandez, 1996).

The predominant race/ethnicity of the biological mothers served by AIA-funded programs is African American (59 percent) followed by White-Not Hispanic (24 percent). In 1995, AIA programs reported that 43 percent of biological mothers served have less than a high school education, 48 percent are receiving AFDC, 42 percent receive late or no prenatal care, 19 percent are HIV positive, and 70 percent use drugs or alcohol during pregnancy.

In both 1994 and 1995, programs reported that the use of cocaine and crack cocaine represent the highest percentage (56 percent in 1994 and 63 percent in 1995) of illicit drug use among biological mothers at program intake. There has been an increase in the use of "other" drugs (e.g., amphetamines, barbiturates, methadone, and PCP) among biological mothers at intake from seven percent in 1994 to 21 percent in 1995. Data were collected on alcohol and tobacco use among biological mothers. In 1995, 40 percent of biological mothers reported using tobacco, 36 percent reported using alcohol, and nine percent reported no use of either substance at intake.

Similar to the data reported on biological mothers, the largest racial/ethnic group of infants and children served by AIA programs is African American followed by Hispanic and White/Not Hispanic. When compared to national averages, infants targeted by AIA programs are more likely to be premature, have a low birth weight, be prenatally drug-exposed, and be infected with the HIV virus. More than half (51 percent) of the index children receiving services from AIA programs in 1995 were reported as being drug-exposed at the time of birth--a figure five to ten times larger than national estimates (Goldberg, Barth & Hernandez, 1996; Shiono, 1996). As a result of the high incidence of cocaine use during pregnancy, cocaine has remained the predominant substance detected in the index child's drug screen results. In addition, close to one-third (31 percent) of the index children were premature compared to the national average of 10 percent (Goldberg, Barth & Hernandez, 1996; Center for the Future of Children, 1995).

Approximately .04 percent of all infants in the United States are HIV-positive (Goldberg, Barth & Hernandez, 1996; Centers for Disease Control and Prevention, 1995); among the AIA program index children, 12 percent are infected with HIV.

Child protective services (CPS) has had a significant involvement in the lives of the index children entering AIA programs. In 1994, 70 percent of index children had been referred to or had some

involvement with CPS prior to entering an AIA program. The number of CPS referrals decreased to 65 percent in 1995. While the index child is enrolled in an AIA program, however, CPS referral rates are much lower (14 percent in 1994 and 22 percent in 1995).

Assistance in keeping families together and providing permanency for index children remain important goals for AIA programs. In 1995, 39 percent of index children were living at home with a biological parent at the time of intake. Upon termination from the program that number rose to 43 percent. Also of significance in providing stability for index children is the decrease in the length of hospitalization. In 1995, 28 percent of index children were in the hospital at intake to the AIA program. Upon termination, only seven percent of these infants/children remained hospitalized.

AIA Services and Practices

The clients served by the AIA programs are among the neediest in the health and human services system. The challenge for AIA programs is substantial, as therapeutic interventions are aimed to help infants, other children, and families recover from the effects of chemical addiction, homelessness, HIV/AIDS, and poverty. The services which constitute the core of innovative AIA programs for drug- and HIV-affected families include:

- **Interagency collaboration** to coordinate service development and funding between multiple agencies serving the same population;
- **Intervention teams** which bring together professionals from a variety of disciplines in the planning and delivery of services;
- **Peer services** which uses paraprofessionals from the community to provide outreach, education, and supportive services;
- **Home-based services** which provide educational, supportive, and therapeutic services in the home of the client;
- **Culturally appropriate and women-focused services** which adapt therapeutic interventions to reflect the cultural and ethnic influences in the lives of families and meet the needs of women, particularly those with young children;
- **Coordinated medical and social services case management** to reduce medically unnecessary hospital days and expedite hospital discharges to the most family like settings; and
- **Legal, policy and program development** to promote permanency for HIV- affected children and to help keep children orphaned by AIDS from entering the child welfare system when other resources can be identified.

AIA programs provide comprehensive services which include, but are not limited to, case management, outpatient and residential drug treatment, HIV screening and assessment, foster family care, family support services, parenting skills training, in-home support, respite care and crisis intervention support, counseling, and recruitment and training of health care and social service providers, foster care families, and residential care providers.

In 1995, case management was the predominant service provided either directly by AIA programs or indirectly by referral. A total of 89 percent of AIA clients (biological families) received case management, 85 percent of which was delivered by AIA programs directly. Seventy-one percent of the families received entitlement assistance, 66 percent received in-home services, and 51 percent received parenting education and support services. Thirty-seven percent of the families received HIV education/prevention services, of which 33 percent was delivered directly by AIA programs. In the same year, 30 percent of the AIA families received HIV screening/assessment. In both 1994 and 1995, approximately one third (31 percent) of clients fully completed AIA services.

Outcomes

In order to examine the effectiveness of AIA-funded programs, there is a need to focus on service delivery outcomes. In an effort to move forward and better reflect the impact of services provided to clients, the National AIA Resource Center, in conjunction with independent program evaluators and the Children's Bureau, is focusing more on client outcomes. The National AIA Resource Center is in the process of revising the Summary Statistics tool to track outcome changes on an individual client level. The revised instruments will track the AIA client from intake through termination from the program, and will follow the client for six months after completion of services. Issues to be continuously assessed during this period will include substance abuse, treatment/recovery, family functioning, child development, and permanency placement. By focusing on individual outcomes over time, the efficacy of AIA-funded services will be better assessed, evaluated, and refined.

Fortunately, it is not necessary to wait for additional years of data to accumulate. The AIA programs have their own evaluations and their talented teams of evaluators and program staff have been gathering information about local outcomes since the first year of the AIA program. The National AIA Resource Center initiated the production of this monograph so that information about AIA program outcomes would be readily available to program developers, practitioners, and decision makers. The chapters included within are a good reflection of more general AIA program practice.

Monograph Chapters

This monograph is based on papers prepared by principal investigators, evaluators, and other staff members of AIA-funded programs. The purpose of the monograph is to share experiences and outcome measurements from selected AIA-funded programs in an effort to increase understanding of service and program effectiveness. The nine chapters of the Outcomes Monograph are divided into three sections organized around common issues concerning service outcomes for drug- and HIV-affected families. The chapters are arranged from the micro-oriented (e.g., individuals and families) to the macro-oriented (e.g., program organization and policy implementation) levels. It is important for service providers, administrators, and public policy analysts to understand the common interests concerning substance use- and HIV- affected individuals, families, and communities before one can apply relevant knowledge towards amending program implementation and changing public policy. Section One, "Maternal and Child Risk Factors" explores how maternal substance use contributes to risk for women and their infants. Section Two, "Child Developmental Outcomes" concentrates on the effects of substance use and HIV infection on infant and young child developmental outcomes. The third section, entitled "Program Development and Evaluation Outcomes," focuses on program development and policy outcomes within the context of service outcomes for drug- and HIV-affected families.

Section One: Maternal and Child Risk Factors

Chapter One, "Psychological Influences on Interactions Between Cocaine-Using Women and Their One Month Old Infants," is concerned with the maternal/child dyad and how substance use,

specifically cocaine, affects maternal/child bonding. Blackwell, Kirkhart, Schmitt, and Kaiser examine the influence of maternal social support, maternal cocaine use, and psychiatric status on maternal/child interaction. Data are presented on twenty-three women enrolled in two case management programs for substance-using pregnant/postpartum women in New Orleans, Louisiana. The study found a positive correlation between years of maternal cocaine use and perceived maternal support as well as psychiatric pathology and perceived maternal support. The authors assert that a combination of years of cocaine use with either a woman's perceived social support or psychiatric status measured during the prenatal period effects the quality of maternal feeding interactions between mothers and their one-month infants.

In Chapter Two, "Maternal Crack Use: An Evaluative Strategy for a Population at Risk," Greenfield, Moore, and Flanagan-Dodge describe the Parent Empowerment Project (PEP) in Miami, Florida and the Indigenous Outreach Model to reach maternal crack users. The model seeks to identify and assess social networks of substance abusers in community settings by using peer modeling, integrates needs assessments with targeted services and referrals, and advocates for the community-based continuity of care. The authors conclude that the street-based intervention of the PEP Program was valuable in reducing risk behavior, as demonstrated by the reduction in the number of pregnancies, births, births of drug-exposed infants, and use of drugs among participating mothers.

Section Two: Child Developmental Outcomes

Chapter Three, "Developmental Outcomes in Infants at Risk," explores various developmental outcomes for infants at risk from prenatal exposure. Hitchcock and Sackor assert that prenatal drug exposure, HIV infection, and prematurity potentially impact the physical, cognitive, emotional, and social development of an infant. Moreover, these infants are often further at-risk due to poor parenting, possible separation from the primary caregiver, and oftentimes multiple placements in foster care. Given the complexity of these issues, a thorough developmental evaluation within a multi-disciplinary approach must be included in a comprehensive assessment of the strengths and needs of the infant and family. The authors begin by describing the risks caused by prenatal substance exposure and the effect drugs and alcohol have on infant

development. Hitchcock and Sackor describe a specific developmental evaluation procedure for the at-risk infant which includes formal mental, motor, and behavioral assessment, presenting case data from Hudson Cradle in New Jersey, a transitional residential, AIA-funded, home for infants awaiting foster care. Finally, the authors discuss strategies for programs serving high risk families, including promoting family involvement, linkage with community services, and staff development.

Chapter Four, "Developmental Outcome of Infants and Young Children with Prenatal Alcohol and Drug Exposure," explores the variation in developmental outcomes for children prenatally exposed to drugs or alcohol. Hsi, Clarke, and Bouchard posit that the answer to the developmental variation in children with prenatal alcohol and drug exposure (PADE) lies in the interaction of environmental, psychosocial, developmental, behavioral, biologic, and medical factors rather than the prenatal drug/alcohol exposure alone. The authors contend that different combinations of risk factors have a cumulative damaging effect on child development. Hsi, Clarke, and Bouchard cite developmental outcome trends of thirty children (from birth to Head Start enrollment) from a five-year study of The Los Pasos Program in Albuquerque, New Mexico. The Los Pasos Program's effort has been towards maintaining family permanency while ensuring the safety and developmental needs of infants and their families affected by substance abuse. Finally, the authors discuss the implications for intervention with this population and future directions for service providers.

Section Three: Program Development and Evaluation Outcomes

In Chapter Five, "Evaluation of Project Lagniappe, Children's Hospital of New Orleans," Brumley, Kissinger, Blackwell, Kendall, and Kaiser present a cross-sectional evaluation of a case management program serving children born to substance-using and/or HIV-infected women, using a mixture of qualitative and quantitative methods.

The results of the study revealed that: (1) multiple risk factors (e.g., poverty, maternal drug use, and HIV infection) affect decisions about caregiving; (2) families under stress tend to function in a cyclical manner (i.e., crises trigger drug use and drug use triggers the transferring of children into

the care of others) and (3) children at-risk for abandonment are most often placed in non-maternal care. The authors are careful to distinguish non-maternal care and child abandonment, stating that non-maternal care may have a positive influence on child development. Finally, the authors advocate for future program efforts to be child-centered and the continuation of extended family foster care.

Chapter Six, "Operation PAR: Long-Term Treatment for Women and Their Children: Process Evaluation and Research Findings," describes a treatment program for women affected by substance use in St. Petersburg, Florida. For the past decade, Operation PAR (PAR Village) has been a national leader in developing a service continuum for alcohol and substance abusers. Coletti, Hamilton, and Donaldson examine the history and development of Operation PAR's women's services. The authors present an overview of research findings conducted since 1986 on substance abusing women clients of PAR Village. Over a five-year period, PAR Village noted great fluctuations in the numbers of substance abusing pregnant women referred to its continuum of services. Events such as the precedent-setting case, *Jennifer Johnson v. State of Florida*, led to the prosecution of pregnant substance abusers and the reduction in prenatal services referrals. The chapter concludes with predictions for the field of substance abuse treatment for women and their children based upon funding trends, changing societal values, and social policy changes.

In Chapter Seven, "Progress Toward Permanency for HIV-Affected and Substance-Exposed Children in the Child Welfare System: Illinois' Project 'First Love' Community-Based Hospital and Foster Care Programs," Coon and Boxer provide case examples and an analysis of clients who are served. The authors focus on permanency outcomes for children affected by the AIDS epidemic in Chicago, Illinois using staff observation and outcome data.

Chapter Eight, "Helping Families Make the Transition from Hospital to Home Care: Evaluation of a program for families of Technology-Dependent Children," discusses the needs of medically fragile and technology-dependent infants and their families. Townes-Rosenwein, Cataldo, and Rossky focus on the backgrounds and characteristics of children who become chronically technology-dependent while in the Neonatal Intensive Care Unit (NICU). The authors address

the difficulties of measuring parents' attachment to these children with special needs. Finally, the authors present outcome results of the Ken Crest Children and Family Services, a program in Philadelphia, PA., designed to alleviate attachment difficulties for families transitioning from the hospital to home care.

Chapter Nine entitled, "What Makes a Program Work? The Effect of Location, Community Relationships, Management Structures, and Organizational Commitments on Program Success," compares two distinct AIA program models, (i.e., hospital-based and community-based) for delivery of services to substance abusing women and children in the New York metropolitan area. The two models allow for the provision of very different services because of the constraints of the service setting. The hospital-based program focuses on internal referrals and assistance with obtaining services outside the hospital setting. The community-based model provides traditional case management to children and their families. Pulice and McCormick evaluate each model with respect to administrative structure, agency reputation, service delivery, and advantages and disadvantages.

Herein lies a snapshot of the risk factors of the drug-and HIV-affected clients served by AIA-funded programs, and data documenting program effectiveness in meeting clients' needs.

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Section One:

Maternal and Child Risk Factors

PSYCHOSOCIAL INFLUENCES ON INTERACTIONS BETWEEN COCAINE-USING WOMEN AND THEIR ONE-MONTH OLD INFANTS

Patricia Blackwell, Ph.D., Kathryn Kirkhart, Ph.D., Dorren Schmitt, Ph.D., Michael Kaiser, M.D.

Background

The influence of maternal cocaine use on parenting behavior and child development has been the subject of increasing scientific inquiry. In these investigations however, it has been difficult to disentangle the relative influence of maternal substance use from other maternal risk factors that commonly accompany addiction. In addition, the duration of maternal substance abuse and its effect on parenting has been seldom regarded. The purpose of the present study was to investigate the influence of maternal psychiatric functioning, perceived social support, and years of cocaine use on the quality of mother-infant interaction measured at one postnatal month.

Psychiatric Status and Social Support

Cocaine users have a higher incidence of psychiatric pathology and mental health problems, including depression, relative to the general population (Bays, 1990). Compared to normative samples of women, crack-using women have entered treatment with higher rates of psychopathology on the SCL-90 (Symptom Checklist-90), with depression, paranoid ideation, and obsessive-compulsive subscales most elevated (Sterling, Gottheil, Weinstein, & Shannon, 1994). Killeen, Brady, and Thevos (1995) found that anxiety disorders were more prevalent in treatment noncompliers among pregnant or postpartum women in inpatient substance abuse treatment. In addition, cocaine-using women scored higher on the Beck Depression Inventory (BDI) than did non-users (Hawley & Disney, 1992; Woods, Eyler, Behnke, & Conlon, 1993;

Woods, Behnke, Eyler, Conlon, & Wobie, 1995) and demonstrated more depressive symptoms than did male users (Griffin, Weiss, & Mirin, 1989). Strickland, James, Myers and Lawson (1993) found that women who used cocaine during their pregnancy scored significantly higher on the BDI at postpartum than did a comparison group of demographically similar, but non-using, postpartum women. A large body of research demonstrated that maternal depression can negatively influence parenting quality and child development (Gelfand & Teti, 1990; Tronick & Field, 1986).

In addition to depression, concerns about the influence of inadequate social support among cocaine abusing mothers has been expressed. Comfort, Shipley, White, Griffith, and Shandler (1990) found that social support was the primary need indicated by homeless, poly-drug using women in three treatment programs. In high risk populations, social isolation has been associated with child abuse and neglect (Polansky, 1985; Saulnier & Rowland, 1985). Moreover, inadequate social support has been associated with impaired parenting ability on substance-using women. Marcenko and Spence (1995) identified combined influences of maternal substance abuse, experience of abuse during childhood, and maternal perception of poor parental support as predictive of child placement outside of the home.

There is evidence that the quality of maternal social support may also influence mother-infant interaction. In one example, Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) found that maternal social support moderated adverse effects of stress in mothers of premature and fullterm infants. In their study, the quality of social support measured at one postnatal month significantly predicted the quality of mother-infant interaction at four months. In a substance affected sample, preliminary findings indicated a relation between perceived social support and mother-infant interaction (Schuler, Black, & Starr, 1995). Thus social support may be an important mediating variable with regard to parenting quality in high risk dyads, (e.g., substance using women and their infants).

Mother-Infant Interaction in Cocaine-Affected Dyads

In addition to inadequate maternal social support, the quality of mother-infant interaction in cocaine-affected dyads may be compromised by a variety of psychosocial factors including poor parenting models, maternal depression, and psychological unavailability. These factors can negatively influence a mother's ability to read and respond adequately to infant cues in feeding and teaching interactions (Barnard et al., 1989). However, as in any dyad, each member of the pair affects the quality of interaction. Behaviors of some cocaine-exposed infants such as irritability, muscle rigidity, and high-pitched cries (Bingol, Fuchs, Diaz, Stone, & Gromisch, 1987; Burkett, Yasin, & Palow, 1990; Cherukuri, Minkoff, Feldman, Parekh, & Glass, 1988), may interact with maternal factors to inhibit optimal bonding and interactions. High quality interactions may therefore be especially compromised in cocaine-affected dyads because both members of the pair are likely to contribute behaviors which inhibit reciprocity. A growing body of research has contributed findings that interaction in cocaine-affected dyads may be seriously compromised (Blackwell, 1994; Free, Russell, Mills, & Hathaway, 1990; Gottwald, & Thurman, 1994). However, not all investigations have revealed that parenting quality is impaired in substance using mothers. Neuspiel, Hamel, Hochberg, Greene, and Campbell (1991) reported no differences in maternal or infant interactive behavior between a sample of cocaine-exposed infants and a substance-free control group. Although maternal addiction was a risk factor, other specific variables such as perceived isolation, prolonged substance use, or psychiatric status may have mediated the effects of maternal addiction on parenting behavior.

The purpose of the present study was to investigate the influence of years of maternal substance use, psychiatric status, and social support on maternal-infant interactive behavior in a sample of drug-using women. It was expected that participants would have impaired social support and psychiatric functioning related to their substance use. Furthermore, duration of substance use was predicted to interact with social support and psychiatric functioning to influence the quality of women's interactions with their infants.

Program Overview

The investigation involved participants who were originally enrolled in the Collaborative Approach to Nurturing (CAN) Program. CAN was funded in 1990 by the Center for Substance Abuse Prevention (CSAP) to Children's Hospital of New Orleans as a five-year demonstration project for pregnant and parenting cocaine-using mothers and their infants. The funded interventions were case management and developmental services. As CAN was phased out, the service model developed in that program was replicated in Project Lagniappe, funded in 1993 by the U. S. Department of Health and Human Services through the Abandoned Infants Assistance Act. In turn, a number of CAN participants transferred to Project Lagniappe. Information about participants, including a range of demographic and psychosocial variables, was collected. In addition, the quality of a standardized mother-infant interaction was observed and quantified.

Measures

None of the published social support measures reviewed seemed appropriate for a population of low-income, substance using women. The Interpersonal Support Evaluation List (ISEL), a 40-item instrument developed by Cohen, Mermelstein, Kormack, and Hoberman (1984), targets various dimensions of social support but does not meet criteria for brevity and educational appropriateness. The assessment was modified through standard instrument design techniques. The revised instrument, Children's Hospital Maternal Social Support Scale (CHMSSS) was designed to measure social support specific to low-income, substance-using mothers. Using this instrument, a pilot test was conducted with 48 women of child bearing age of similar educational background and socioeconomic status to CAN/ Lagniappe participants. Using data from this pilot test, a principle component factor analysis, as well as an analysis of internal consistency, was performed. Guided by the results of these analyses, a final revised instrument of 22 items (Cronbach's alpha = .7114), separated into three dimensions including personal support (12 items, alpha = .7144), parental support (5 items, alpha = .7787), and belonging (5 items, alpha = .6998), was produced.

The Brief Symptom Inventory (BSI), an abbreviated version of the SCL-90R or Hopkins Symptom Checklist, was developed and updated by Leonard Derogatis (1993). The BSI contains 53-items that reflect nine primary symptoms and three global indices of psychiatric distress. The Global Severity Index (GSI), has been widely accepted as the most useful of the three BSI indices for research, as it incorporates both number and intensity of distress symptoms. This was the indicator used in the present study.

Kathryn Barnard (1978) developed the NCAST Feeding Scale to measure parent-infant interactions through observation of feeding situations. Composed of 76 items, the scale is organized into six conceptually derived subscales, four describing adult behavior and two describing infant behavior. The most reliable index of mother's behavioral contributions to these interactions is the Mother Total Score. A part of this Mother Total Feeding Score was used in the present analyses.

Method

Participants

Data for these analyses were provided by 23 women at the time of intake interview. The average age of participants was 28.3 years. With the exception of one Caucasian, all participants were African-American. All women were pregnant at time of enrollment, with an average of 3.52 children, and all were HIV negative. Based on self reports, participants had used cocaine for an average of 3.8 years, ranging from one to nine years at time of enrollment.

Procedure

The psychiatric (BSI) and social support (CHMSSS) measures were collected by case managers within one month of program entry. Case managers provided assistance with completion of paper and pencil assessments only if requested by participants.

Mother-infant interaction was assessed at one postnatal month. NCAST standardized instructions were provided (Sumner & Speitz, 1994); Mothers were instructed to carry out as typical a feeding as possible, to ignore the presence of the examiner during the feeding, and to indicate when the feeding was finished. The interaction was videotaped and coded by an NCAST-certified examiner.

Results

Social Support

In general, participants' perceptions of available social support was low, based on their CHMSSS responses. The raw total scores for the 23 participants ranged from 34-77 on a scale of 0-88 ($M = 46.5$). Of the four choices on the Likert Scale, "Always True, Sometimes True, Seldom True, or Never True" the average response was "Seldom True", indicative of generally inadequate support.

Psychiatric Status

Twenty-one women participated in a BSI administration upon enrollment ($M (GSI) = 62.4$, $SD = 11.6$, range = 39-80). This group's mean GSI score indicated a level of psychiatric disturbance at the 86th percentile when compared to norms for a non-inpatient female population. Using another standard indicator of "caseness" (a GSI T- score above 63), 57 percent of the 21 clients met this screening criteria for positive psychiatric diagnoses. Obviously, mental health was more impaired for these women than in non-patient populations.

Mother-Infant Interaction

At one postnatal month, all dyads participated in the NCAST Feeding assessment (NCAFS). The mean Mother Feeding Total was 32.2 ($SD = 5.9$, range = 21-42). In comparison with established norms, 60 percent of the participants had Mother Total Feeding Scores at or below the 10th percentile, which has been established by Barnard as the "worrisome" range for African American dyads (Barnard et al., 1989). Maternal interactive quality at one month was therefore impaired in the present sample.

Correlation Analyses

Results of Pearson Product Moment Analyses relating years of cocaine use, perceived social support, psychiatric status, and quality of maternal interaction during a feeding situation revealed two significant correlations. First, years of maternal cocaine use and maternal social support were positively related ($r = .446$, $p < .05$), indicating that women with briefer histories of drug use had less positive perceptions of their support structures. Second, GSI and maternal social support were also positively correlated ($r = .524$, $p < .05$), indicating that impaired psychiatric status was related to perception of higher levels of social support.

Multiple Regression Analyses

Two separate multiple regression analyses were provided for prediction of the quality of maternal interaction during feeding. Carver (1978) proposed a benchmark for judging effect sizes of the Squared Multiple Regression Coefficient. When a combined effect of independent variables explains 15 to 20 percent of the variance of a dependent variable, moderate clinical significance is established.

In the first analysis, the combined influence of maternal social support and years of cocaine use on maternal feeding interaction was analyzed. Table 1 reveals that 17 percent of the variance in maternal interaction quality was accounted for by perceived social support and years of cocaine use ($R^2 = .173$, $p = .149$). Therefore, although statistical significance was not achieved in these results, they be considered clinically significant according to the Carver (1978) benchmark.

Table 1

Results from Regression Analysis with Variance
Accounted by the CHMSSS and Years of Cocaine Use

	SOS	DF	MSS	F-Ratio
Regression	132.5	2	66.25	2.09
Residual	632.8	20	31.64	

A second multiple regression analysis was conducted to investigate the combined influence of maternal psychiatric status and years of cocaine use on maternal feeding interaction. Once again, this regression analysis, presented in Table 2, did not result in statistical significance. Evidence of clinical significance occurred, however, in that 19 percent of the variance in maternal interaction quality was explained by years of maternal cocaine use and maternal psychopathology, as indicated by the GSI ($R^2 = .193$, $p = .146$).

Table 2

Results from Regression Analysis with Variance Accounted
by the GSI and Years of Cocaine Use

	SOS	DF	MSS	F-Ratio
Regression	136.68	2	68.34	2.15
Residual	572.46	18	31.8	

It is probable that small sample size ($N = 21$ and $N = 23$) compromised power in these two multiple regression analyses. In each case, the eta squared statistic suggested that observed relationships may have reached statistical significance with larger samples.

Discussion

As predicted, participants in the present sample generally indicated a perceived lack of social support and impaired psychiatric status. In addition, the quality of maternal interaction at one month postpartum was in the high risk range as established by NCAST guidelines (Barnard et al., 1989). However, there did not appear to be a linear relationship between years of maternal cocaine use and interaction quality. Instead, more complex relationships were revealed between maternal cocaine use and social support or cocaine use and psychiatric status in relation to mother-infant interaction quality at one postnatal month.

Psychosocial Variables

A significant positive correlation was found between years of maternal cocaine use and perceived maternal social support. It was predicted that a negative relationship would emerge between years of cocaine use and social support, due to the destructive effect drug abuse has on friendships and family bonds. The results instead suggest that a support structure may be perceived within the context of drug use which may be strengthened by the duration of use. That is, drug "culture" and professional supports may replace the typical support provided by family or friends. Investigation of support structures and types of support within the context of drug use seems an important avenue for future research.

The positive correlation between maternal social support and the GSI (the index of psychiatric status) was also surprising, given that an inverse relationship between social support and psychopathology is most commonly presented in the literature (Bays, 1990; Hawley & Disney, 1992; Woods, Behnke, Eyler, Conlon & Wobie, 1993). We speculate that the support perceived by participants in their involvement with CAN staff occurred at the same time they were confronting the need to reorder their lives in the wake of addiction. Therefore, some measurable social support occurred along with depression and anxiety within the circumstances of their lives one month after enrolling in a recovery program. It is possible that women with more significant mental health problems, perceived stronger immediate support within the context of the program than did women with less psychiatric distress.

Mother-Infant Interaction

Maternal reciprocity (Brazelton, Koslowski, & Main, 1974), contingency (Beckwith, Cohen, Kopp, Parmalee, & Marcy, 1976; Crockenberg, 1983), responsiveness (Clark-Stewart, 1973), eye contact (Stern, 1974), verbal exchange (Osofsky, 1976), and tactile/kinesthetic stimulation (Korner, 1974) have been shown to be important aspects of mother-infant interaction. In turn, feeding situations have been considered rich opportunities to observe each of these qualities of interaction. It has been established in non-substance affected populations, that impaired mother-

infant interaction is related to compromised cognitive development (Beckwith, Cohen, Kopp, Parmalee, & Marcy, 1976; Bee et al., 1982; Crockenberg, 1983; Olson, Bates & Bales, 1984). Higher-quality mother-infant interaction has been associated with enhanced cognitive development in drug-exposed children as well. In a sample of methadone-maintained mothers and their infants, mothers' interactive behavior was a significant concurrent predictor of Mean Developmental Index from the Bayley Scales of Infant Development when the infant was twelve months old (Bernstein, Jeruchimovicz, & Marcus, 1986). Implications of the level of impaired maternal interaction evident in this sample during feeding interactions at one postnatal month is unclear, and warrants further investigation.

The present study provided evidence that factors associated with maternal substance use affect the quality of mother-infant interaction. Years of cocaine use is not directly associated with the quality of interaction. Instead, a more complex interaction of years of substance use in combination with psychosocial factors is correlated with maternal interaction behavior.

Researchers have only begun to investigate the long term effects of prenatal cocaine exposure. Developmental effects of substance abuse in combination with associated psychosocial variables is even less well understood. As the body of research on parenting of substance-using mothers accumulates, compelling evidence is provided that substance use is only one of many risk factors to be considered. That is, families enrolled in CAN and Lagniappe are clearly dealing with multiple risk factors in their everyday survival. Risks including poverty, community violence, cycles of abuse, poor parenting models, and maternal psychosocial needs are often present where reported drug use occurs. If parenting and child development are to be more clearly understood in these families, maternal substance use and the developmental effects of prenatal drug exposure must be considered in the larger and ongoing context of compounded risk.

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MATERNAL CRACK USE: AN EVALUATIVE STRATEGY FOR A POPULATION AT RISK

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Introduction

The work of the National Abandoned Infants Assistance Resource Center at the University of California, Berkeley, corroborated what our local independent evaluation team of the Miami based Parent Empowerment Project (PEP) concluded in our second and third year program evaluations. The Center's findings confirmed that evaluations of street-based programs across the country experienced great difficulty in gathering quantitative data utilizing a comparison group design, due to the highly mobile nature of this severely, economically, and educationally disadvantaged population whose environment is constantly shifting.

The result for the PEP evaluation team was an absence of reliable statistical evidence that could be generalized to accurately describe program participant outcomes. Efforts to generate a valid comparison group in south Florida were further exacerbated by the impact of Hurricane Andrew. We were unable to locate and thus utilize a comparative risk group methodology. Nonetheless, our study results did point to the fact that the street-based intervention of the PEP program was valuable in reducing risk behavior, as demonstrated by a reduction in the number of pregnancies, births, births of drug-exposed infants, and use of drugs among participating mothers.

Thus, quantitative measures were helpful in establishing the number of people seen, their risk behaviors, number or services each participant received, and the number of referrals actually made in opened cases. However, only qualitative data can provide the rich context in which to understand and interpret the nature of PEP team interventions and the complexity of interactions that constitute service delivery. Without an appreciation of how services are provided and thus

how a program is implemented, all information about outcomes becomes ephemeral, tied to a particular program and service setting, and not amenable to generalization (Doueck, Bronson, & Levine, 1992).

Indigenous Outreach Model

Gaining access to communities and understanding the context of risk behavior are both important and necessary precursors to successful prevention interventions. Only once this is understood can risk reduction messages be transmitted and assimilated by the target group (Dorfman, Derish & Cohen, 1990).

In that the PEP project is designed to provide intensive services and support to mothers, whose children have been exposed to drugs, through the use of indigenous social work aides (who are themselves in recovery), PEP clearly falls within the category of interventions labeled as an indigenous outreach model. Thus, to understand, interpret, and evaluate the PEP program, one must understand the theoretical basis of the intervention strategy.

The Indigenous Outreach Model was conceived in 1977 by Dr. Patrick Hughes for research and intervention in community heroin epidemics (Hughes, 1977). According to the author, this model offers several advantages: (1) a systematic methodology for identifying and accessing social networks of substance abusers in community settings; (2) the use of peers to influence individuals and social networks by modeling and encouraging risk reduction behaviors; (3) a system for integrating needs assessments with targeted services and referrals; and (4) an integrated framework to provide community-based continuity of care that includes identification, contact, assessment, treatment, service referral, aftercare, integration back into community, and the opportunity for the consumer to give back service to the community.

Indigenous workers are characterized by: the possession of social environmental and ethnic qualities of a subculture; the ability to share with a client population similar verbal and nonverbal language; an understanding of community health beliefs and barriers to services; heightened empathy with targeted consumers; and a feeling of responsibility towards a community and its

needs (Westheimer, 1970; Hai-Yahia, 1984; Callan & Franklin, 1972; Gartner & Reissman, 1971; Conn, 1968).

Indigenous workers are used to provide a liaison between professional health care services and hidden, reluctant, or hard to reach populations by providing an individual who can have a credible role in the life of a client (Siblin, 1989).

Although the use of indigenous paraprofessionals to perform community-based substance abuse intervention activities seems to be ideal, the literature does caution that this approach has possible drawbacks such as: (1) confusion about workers' roles as paraprofessionals relative to services provided by professionals, (e.g., case management activities, etc); (2) paraprofessionals being accepted by their clients, and (3) relegation of the paraprofessional to menial tasks by agency personnel, e.g., telephone use and clerical work. Other cautions in dealing with client's include: (1) the possibility of projection; and (2) a possibility of psychological contagion (Poland, Giblin, Waller, & Bayer, 1991; Reissman, 1965). Despite these potential concerns, qualitative evaluation of the PEP program clearly indicates that indigenous outreach workers were successful in their outreach efforts and positively impacted the outcomes of clients in the program.

Nevertheless, as emphasized in the literature, training is a critical element necessary to enhance the role of outreach workers. Another important element is providing supervised case management of client cases by professionals who are sensitive to the para-professionals and the issues of self awareness in the outreach workers (Reissman, 1965; Siblin, 1989).

Research Questions

Research questions included:

- What exactly is the PEP intervention and how is the intervention carried out?
- What services are actually offered by PEP?
- What are the rates of getting clients into the PEP program compared to other programs?
- How do PEP clients differ from State of Florida clients?

The remainder of this chapter discusses how PEP's evaluation team attempted to answer these questions and addresses the implications and appropriateness of these questions for a population of mothers addicted to crack.

PEP Intervention

The initial proposal for PEP presented an overview of the program, mentioning that an evaluative component would be included, but no specific research designs or questions were identified. Developing an evaluative strategy after the fact is not as effective as a prospective design. Ex post facto measures tend to be biased, favoring program administrators' and staff's perceptions or agendas, rather than the sponsoring stakeholder's.

PEP Services

Most of the services offered by the PEP Program were contracted or brokered out to other programs and agencies. The case manager provided the indigenous workers with information and brokered services. Except for the Data Dads and the PEP teams doing home visiting and peer counseling, little else was provided at PEP. PEP flexible funds were used to pay: isolated utility bills for clients, random drug screening, and the teaching of Life Skills.

PEP Clients

PEP clients are a sub-group of the state clients. They are women that have delivered at least one substance-exposed newborn in the year preceding each evaluation. Of the 73 clients with complete files, 39 clients represent enrollees from 1991 and 1992, and 34 clients represent enrollees in 1993. Group composition includes African Americans (88.3 percent), Hispanics (5.9 percent), other Black Americans (2.9 percent) and Caucasians (2.9 percent). Less than 12 percent are married.

Methods

Sampling

The subjects (n=34) for this study were recruited from the Parents Empowering Parents (PEP) program which is operating under administrative contract to the Children's Home Society Agency, Dade County, Florida. Selection criteria included that women be current consumer/recipients of the PEP indigenous outreach program, and that men be in relationships with such females and the recipients of PEP's outreach efforts.

A non-probability purposive sampling procedure was utilized in that subjects were approached routinely during a scheduled PEP outreach visit. The participants were drawn conveniently by the researcher while accompanying each of the five PEP teams and a Case Manager on their weekly rounds. This sampling method was selected by the researchers, in collaboration with the PEP staff, to yield the richest possible data.

All of the PEP women and men were in varying phases of either the addictive or recovery process. All of the female participants had delivered a substance-exposed newborn in Florida's HRS District 11, and all of the male participants were either the fathers of these infants or the current partners of the female participants.

The field researcher attended the PEP team's weekly staff meetings to introduce herself and familiarize the teams with the concept of gathering data by participant observation. The researcher explained that in order to capture and describe the interactions between PEP teams and clients, she would need to accompany each team for at least a day as they made their scheduled outreach visits. At the staff meetings, the researcher and PEP team members constructed a plan of where and when to consecutively meet each of the teams over the following six weeks for data collection.

Measures and Data Collection

Due to the sensitive nature of the data to be collected and the population being observed, tape recordings of the scheduled visits were abandoned in favor of field notes. After each visit, the researcher, in the privacy of an automobile, would write field notes of the encounter. Notes on 21 team contacts were made. These written notes were to be as objective as possible, however, it was realized up front that subjective bias would in fact take place. The field researcher's subjective perceptions created the indicators of how the outings proceeded. The primary purpose of describing the PEP team interactions with their clients in order to replicate this intervention was accomplished. Previously, replication was not possible due to an incomplete intervention description.

From the ethnographic field notes, a tally sheet for each of the intervention levels was constructed to facilitate content analyses. Prominent variables emerging from the written notes define each level of intervention. Note that there are five PEP teams (including the Data Dads) and four levels of intervention referred to as the PEP Laddering component. Level 0 includes active drug users being recruited; Level 1 indicates that detoxification has been completed but clients are still in treatment and needing a lot of support; Level 2 includes clients returning to their community, a half-way house or outpatient treatment; Level 3 indicates that the client demonstrates visible and obvious signs of a stable drug-free lifestyle. For each level, qualitative data were transformed from tally sheets into dichotomous quantitative data. Since the intervention has only recently been adequately defined, this methodology is primarily exploratory in that it identifies patterns on each level to facilitate the formulation of descriptive data.

As stated, the PEP teams operate on different levels and/or functions. All of the teams are familiar with each level, but each focuses on one or two levels at a time. Every few months, the focus of each team, except the Data Dads/Paramour team, changes to a new level. This rotation of levels is utilized to prevent burnout by the PEP teams, particularly since the lower levels (0, 1) do not provide the positive feedback that higher levels provide (2,3). Two teams are assigned to Level 0; one team to Level 1; and one team working with both Levels 2 and 3. The Data Dads/Paramour

intervention has two male outreach team members assigned, and the Case Manager/Treatment Specialist Level has two females, a Case Manager and her assistant assigned. The field researcher chose one interaction (between PEP team members and a client) at each of the four levels, Level 0 through Level 3, the Data Dads intervention, and the Case Manager function to be representative of that intervention effort. Each of the six interactions is represented by a narrative vignette recorded and cross-checked by the researcher and team members. Each vignette reflects the natural occurrences during that interaction, the subjective sensory perceptions and interpretations of the researcher, the local dialect, and the elicited reactions of clients and their family members.

The tally list consisted of prominent variables that emerged across all levels during observation. Similarities and differences were used to construct patterns which are the foundation of this inductive research. These emerging variables are in qualitative form but coded numerically to create a content analysis of each level of the intervention.

All program staff and participants knew that observations were being made for evaluation purposes of the project. The field researcher related personal experiences as a maternal substance abuser to program staff and participants in order to gain the trust and confidence necessary for this study. Relating her progress in recovery and continuing education as a doctoral candidate was believed to be helpful in demonstrating the potential to be found in recovery.

In addition to field observations, other methods used to collect information included:

- Archival Research of PEP records. This research determined the number and types of services that the 73 clients received.
- Interview with the program director was conducted to determine the number and types of services provided for the (112 according to Administrator's files) active clients, 39 of whom represent prior years' recruitment. No logical response was available regarding discrepancies between archival records and administrative reports on the numbers of clients being served, except that the fault falls on inaccurate record keeping by the Case Manager and PEP Team members.

- Interviews with PEP program staff and outside agencies were sought and recorded to determine the professional level with which they viewed PEP, and to obtain views and suggestions for improving services. Most responses were complimentary to the program.
- SISAR (The Florida State Interim Substance Abuse Report), an informational data base on drug abuse, was used to determine the extent of the maternal abuse problem in HRS District 11, and to look at specific demographics. These data were compared quarterly, semi-annually, and annually for possible trends that could require a change in demand for services.

Participant-Observer Narrative

The following narrative vignette describing a Level 3 intervention is one of six chosen for illustration purposes in the third-year evaluation. This level of intervention is provided by the same team that provides the Level 2 intervention. The methods provided at both Levels 2 and 3 are identical. The differences are in issues discussed and changes in the "clean time" and "number of home visits". Level 2 has at least three to six months clean time and Level 3 has six months or more. Level 2 clients are visited once or twice bi-weekly, while Level 3 clients are visited once a month and have regular telephone contact with the team.

Case Study

As we approached Gail's house, we saw a band of middle-aged black men passing by. One man walked in front and two, laden, solid men walked behind. The two stragglers were "pushing cans." They had shopping carts piled high with aluminum cans. They were headed toward the main road, I was told, to sell these cans to make some money. A few more men pulled up in the driveway, in an old car, and began talking to a small gathering of elderly black gentlemen who were busy talking and nodding amongst themselves. From my perspective, the talking and nodding and general body language took on a subtle but compelling rhythm, leading me to believe the discussion was mostly social.

The well-kept house was bordered low and neat by palm and banana trees. An enormous plastic pool, about the size of a small apartment's second bedroom, was in the front yard. It looked clean, cool, and inviting in this scorching midday sun

It seemed like Gail's house was a magnet, the authorized center of activity. Gail was there in the doorway, making her way to Ovette and me. Gail was friendly, cool but neither frigid nor distant; distinguished, yet without that awful stiffness. She was no longer stalled by the

disease of addiction. Gail presented as a mature, take-charge female. I had the feeling that no one cared for her as impartially as she cared for herself.

Inside, Gail's mother sat in a wheelchair. "Both of her legs had been cut off," Gail explained to me as I was caught looking at her, "cause of diabetes. She just come out of the hospital not long ago. We tried and fix her up to be comfortable to a certain extent."

The smell of black-eyed peas, french fries, and pork chops was enough to leave anyone itching to be fed. Gail led us into the neatly painted kitchen and pointed out that she just finished hanging a wallpaper cornice around the circumference of the kitchen's walls. It had a black background with cheerful cherries, blueberries, and white flowers. This was a warm and charming home.

Ovette asked, "So, how you been doin'?"

"Fine, just fine. So how about you and who have you brought here for me to meet?"

"This here's Karen. She's one of us, in recovery that is, been clean a long time. She's doing research." There was a suppressed murmur from Gail, yet she seemed undaunted and offered me a homemade french fry.

"Say, am I to see you over at the meeting tomorrow?" Ovette inquired.

"You sure enough will. You know I been done tired of being locked up, walked on, jumped on, and stepped on. You know I been done tired of all those things. The things I worry about now is my mama and my son. Did Ovette tell you I got my son in a group home? Just got him in. It took a long time. He's brain damaged. Medically impaired is what 'they' call it. I hope he will be okay over there. I don't like having him so far away, but they say it's the best thing. Sometimes I think of the old days when he was here with us and I store up all my tears and have to steal away to let'em out. I sure do hope he ain't brain damaged cause of my addiction." Ovette had tears in her eyes and reached out and gently touched her knee.

Gail pushed back her tight curly hair and wiped a tear, then continued, "I got two others with me right here, plus a niece. They are plenty to keep me busy. Now I been called to give it away, spread the message that is."

"So, you've been thinking of joining us on the team? You're the most positive and motivated out of them all."

"No, I ain't into joining no team, but I do feel the call to tell these still out there. There are plenty right around here," was Gail's reply, adding, "I need to get me a good paying full-time job, besides. You got any ideas, Ovette?"

"Not off the bat," Ovette said. "But I'll tell the case manager. You know her, Gail, its Dora. You call her and I'll keep it in mind. Something will happen. Meantime, you keep in good spirits like I know you will and I'll see you around at the meeting tomorrow."

They rose simultaneously. It was easy to see that there was a genuine bond between the two.

They hugged each other, and Gail turned and hugged me too. She walked us to the car as her husband and the other men who had been talking breathed a soft, restrained, and bashful salutation.

Discussion

Findings and Conclusions

The first area of research concerned "What exactly is the PEP intervention and how is it carried out?" The intervention is a synergistic effort between para-professional indigenous workers and professional case managers, that focuses on peer counseling, support, and referral. In the case narrative, the PEP team is primarily operating in a support capacity.

The second research question, "What services are actually offered by PEP?" is also clearly set out in tables in the evaluation report. Services, those not brokered to other agencies, include the occasional payment of utility bills for clients, and the teaching of Life Skills.

The third area of research concerned, "What are the rates of getting clients into the PEP program compared to other programs?" This question presumed that similar programs might be measured to determine the level of client participation. At the time of the evaluation, no other program in Miami paralleled PEP in methodology. Anecdotal evidence indicated that PEP was more successful than a program that used indigenous professional nurses for home visits because clients were somewhat put off by uniforms that the indigenous nurses wore, possibly suspecting them of being connected to municipal authorities on some level. PEP is the first program in Miami focusing on maternal substance abuse using indigenous outreach paraprofessionals in conjunction with professional case managers. PEP had no legal mandate to leverage clients into the program, as do outpatient day treatment programs and programs that focus on the drug-exposed infant. According to the PEP program administrator, there were approximately 120 referrals for the fiscal year 1993, of which 88 substance abusing mothers were contacted, and 73 were enrolled (83 percent). Referrals to PEP represent between eight and 10 percent of the reported maternal substance abusers in Florida's District 11. In 1993, District 11 reported 1,365 maternal substance abusers. PEP referrals range from eight to 12 per month, with 10 being the median. This success was, as stated, done without a legal mandate. No enrollment data were collected from other agencies or programs, as they were seen as being too different in scope and mission for

comparison. Thus, the question, "What are the rates of getting clients into the PEP program compared to other programs?" is seen as inappropriate for this study.

The fourth area of research was to determine "How PEP clients differed from other State of Florida clients?" Data from SISAR indicates that clients in District 11 averaged 32 years of age, had two prior admissions, two prior arrests, and spent on average 63 days in inpatient and outpatient treatment. The PEP clients differ in that: (1) PEP clients tend to be young, Black mothers having their first drug-exposed birth; (2) PEP clients tend to have fewer life skills, lower educational levels, face higher rates of poverty, and experience higher rates of disease than the general SISAR population.

The number of outpatient maternal substance abusers in the state has fluctuated in the past few years, falling then rising, likely as a result of drug interdiction efforts. Interestingly, although the average number of days in treatment have declined over the past three years, the number of average prior admissions for substance abuse also dropped for the first quarter of 1994. This trend, if it holds, may indicate that extended treatment periods could work against recovery. Alternatively, seeing women with fewer prior admissions could mean that prevention/interdiction and intervention efforts are narrowing the time between the onset of addiction and intervention.

Program Strengths

The evaluation of PEP revealed the following strengths of its intervention model:

- PEP is seen to be successful in achieving initial contact with an otherwise reluctant or hidden population.
- PEP is capable of maintaining relationships with maternal substance abusers by utilizing indigenous recovering maternal substance abusers.
- PEP filled a gap in services by initiating a community-based Narcotics Anonymous group for current and potential clients.
- PEP started a program to reach out to the male partners of the targeted maternal substance abusers.

- PEP teams demonstrate their recovery to clients by role-modeling positive drug-free behavior and lifestyles while living in targeted communities.
- PEP is the only program in south Florida that uses indigenous outreach in combination with professional case management for this population.
- The PEP program encourages maternal substance abusers still actively using drugs to consider learning drug-free behavior without threat of imprisonment or reduction of financial support (i.e., no leverage is used).
- The PEP program administrator has indicated that 33 former clients are no longer receiving AFDC and are all employed. This success indicator means that they are no longer net users of public assets, but in fact, contributors.

Program Weaknesses

Despite the apparent effectiveness of the PEP model, the following areas could be improved:

- Although initial contact is excellent and relationships are maintained, there are no indicators of the ratio of enrollees to successes of mothers who remain clean from PEP intervention. While this could be seen as an evaluation weakness, the initial program proposals included evaluation and is thus, part of the overall program.
- Teams provide few services other than visiting clients and encouraging recovery.
- Many "paramours" are apparently still abusing drugs, and few discussions recorded with paramours relate to their recovery.
- Additional cost-effective measures could be taken (i.e., reduction of administration costs).
- There are no physical tests done to validate whether or not mothers are in fact Clean and Sober (only team observations) and the program used client reported evidence of employment and AFDC recipient status. One goal, "to reduce the rate of successive substance exposed and HIV involved newborns" can only be measured ex post facto, limiting the availability of currently valid statistical information.

Recommendations and Suggestions

Some of the internal functions within PEP that were observed and require comment are probably best referred to as "growing pains". If PEP, in fact, has 112 active clients that require a great deal

of servicing, the implications are that numerous home visits, telephone calls, plus a number of brokered services are necessary. Home visits require a great deal of traveling between destinations. Travel from downtown Miami to Homestead and back, for example, is approximately 80 miles. PEP team members are paid \$ 7.00 to \$ 7.28 hourly for 20 hours each week. They are given 23 cents per mile for travel. The PEP model as an intervention is unusual; so too are the PEP team members. Team members, it must be remembered, are recovering addicts without assets. Their transportation, in each case, is old and non-reliable. With income low and needs so great, expecting each member to furnish a vehicle and be compensated with 23 cents a mile is unrealistic. Numerous incidents of breakdowns on the road characterize their typical work week. It is admirable that PEP teams continue to push themselves each day to come to work. It is the evaluation team's opinion that additional support for the data teams needs to be considered.

Individual discussions with team members about their transportation difficulties indicated that the administrator had previously tried to remedy the situation by seeking a garage to service the team member's autos. At this time, a garage that would work with the PEP program had not been located. It is recommended that such a garage be found, preferably in the targeted neighborhood, and that each driver be given a monthly allowance (approximately \$ 50) above the mileage fee for the use of their automobile. Alternatively, a search for a car dealership that would possibly donate or lease at a reduced rate should be pursued.

Additional program recommendations and suggestions to help improve services include the following:

- Make linkages with the Health Department to provide perinatal workers, substance abuse nurses and healthy start workers,
- Make linkages with the Department of Criminal Justice for added leverage, providing it does not negate intervention efforts,
- Match each PEP team member with one substance abuse social worker and/or nurse to provide professional nursing and social services in conjunction with peer counseling and recruitment,

- Use some central figure located in the office to make telephone calls to clients and set up home visits where feasible. It is understood that many clients do not have telephones and unannounced visits will be required. But in many instances, the PEP teams could more effectively use their time if they did not have the added responsibility of calling clients. Perhaps, since it is a small program, the administrator's position should be redefined.

Summary

Available data from SISAR, Florida's data bank on maternal substance abusers, indicated a 26 percent increase in maternal substance abuse over the previous six months, reversing a decreasing trend. Projections call for the increasing trend to continue. This indicates that maternal substance abuse is again on the rise and that a larger effort is required in this district to combat this growing social problem.

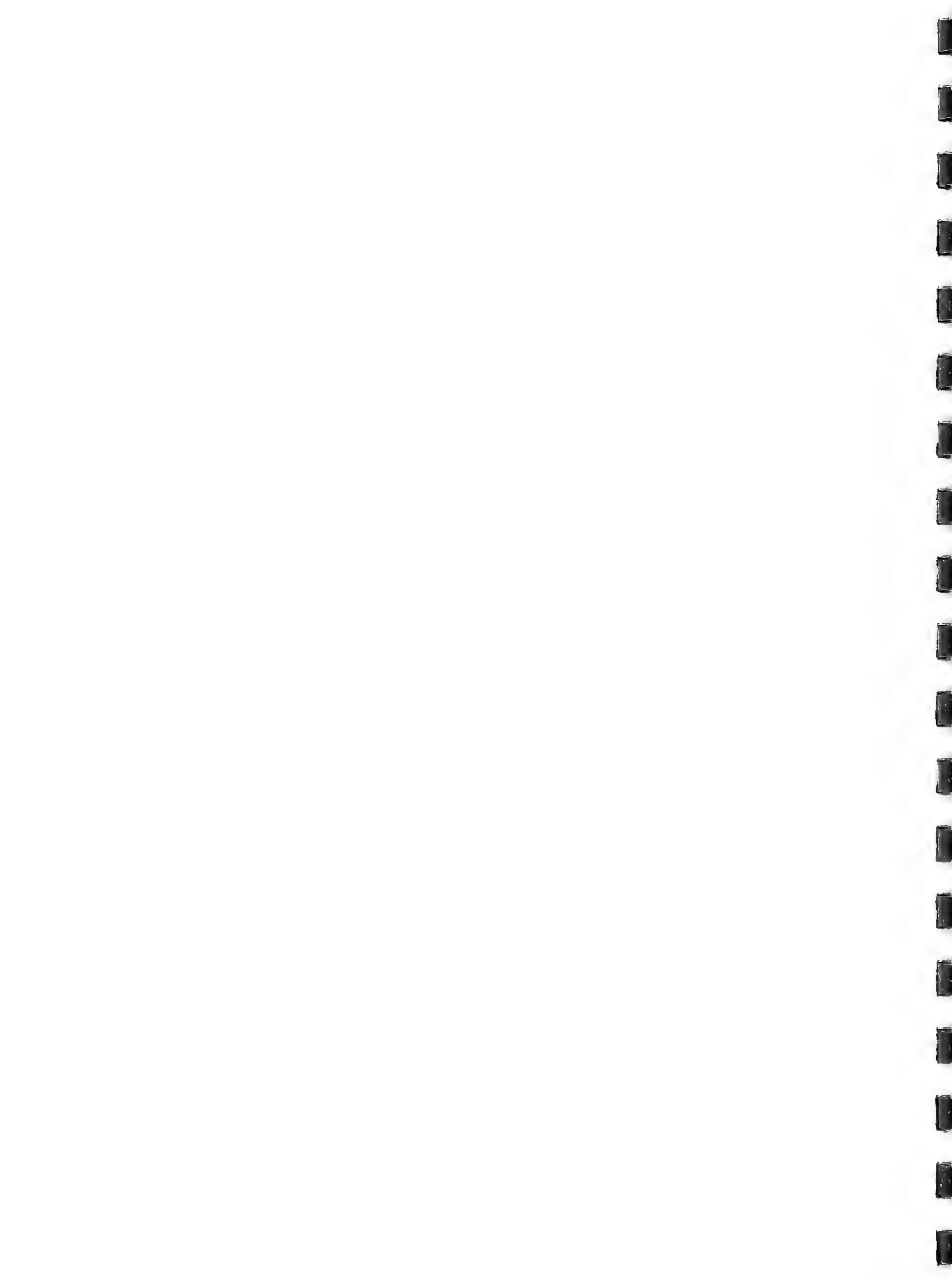
There is no legal mandate for maternal substance abusers to remain involved in recovery once they have had inpatient treatment and minimal outpatient treatment. Most of these mothers eventually repeat their behavior problems and are at risk of even greater medical problems in the course of supporting their addiction.

Readers of this chapter are asked to focus on the valuable service PEP is providing for the community and its replicability rather than specific problems brought to light for internal control requirements. A replication manual has been prepared as a result of this evaluation and is available to interested communities.

PEP partners, whether professionals or peers, are dedicated to building healthy and reliable support systems for clients and their families through personal empowerment, cultural awareness, and community mobilization. This partnership is committed to preserving and strengthening families while improving their quality of life. This study has given the PEP staff, both professionals and para-professionals, the support necessary to implement various changes presently reflected in the replication manual.

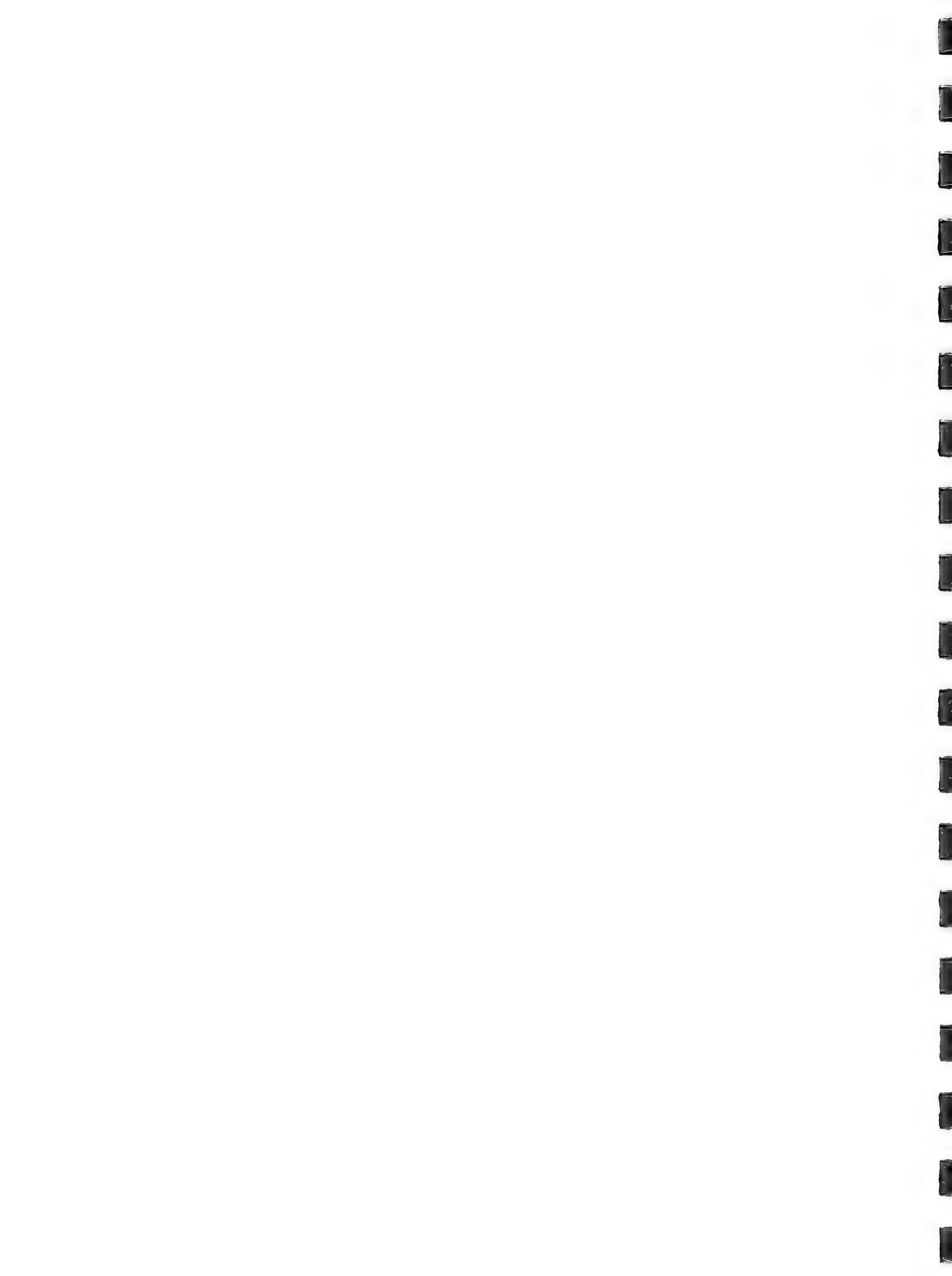
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Section Two:

Child Developmental Outcomes



DEVELOPMENTAL OUTCOMES IN INFANTS AT RISK

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Introduction

From the time of conception, development proceeds along lines dictated by the inherited genetic code and mediated by the environment inside the womb. Certain genetic diseases or chromosomal anomalies can impact on future growth and development. For example, Down's Syndrome most often caused by an extra chromosome, 21, results in characteristically abnormal facial features and mental retardation, and affects other major body systems such as the cardiac system (causing congenital heart disease in 30-40 percent of children with Down's syndrome). Genetics may also influence personality development. Recent research suggests that personality traits, (e.g., tendency toward shyness), can also be part of our genetic inheritance (Batshaw & Perret, 1992).

Of particular concern to staff working with families at high risk is the influence of the mother's lifestyle on the uterine environment prior to the infant's birth. Women who abuse alcohol and other drugs place their infants at risk due to the direct effect of the drug on the developing infant's nervous system. Polysubstance abuse is the norm among women who abuse drugs. Therefore, although we will speak of some commonly used drugs and their individual effects on the fetus, typically these drugs are used together. Their additive effects are unknown. Drugs which harm infants prenatally are called teratogens.

Of all the psychoactive substances which are abused, alcohol is the most teratogenic. Alcohol ingestion during pregnancy is associated with fetal alcohol syndrome, a disorder characterized by mental retardation, abnormal facial features, and personality features such as a lack of awareness of the connection between one's own behavior and the consequences it may bring. Opiates such

as heroin and methadone produce a physiologic dependence of the fetus on the drug. After birth the infant experiences a withdrawal syndrome and must be placed on a detoxification regimen. Cigarette smoking during pregnancy is associated with low birth weight and premature labor.

Much attention has been focused recently on babies exposed to cocaine. The effects of cocaine on development are difficult to separate from the effects of a drug-using lifestyle. Women who abuse drugs are less likely to seek prenatal care (Griffith, 1992). Further, since cocaine is an appetite suppressant, the pregnant cocaine user may not obtain adequate nutrition for the developing fetus. Cocaine-exposed babies are at higher risk for difficulties including irritability, poor tolerance for stimulation, or excessive sleep, and difficulties with arousal (Griffith, 1992). These infants may not be able to tolerate social interaction with their caregivers because they find the interaction too stimulating; they may not make eye contact. Caregivers in turn may be frustrated with their inability to soothe or engage the baby socially and abandon all efforts to develop a positive, attuned relationship with the baby. These early and repeated infant-caregiver relationship difficulties can lead to long-term negative effects on infant social development.

Additionally, drug users often trade sex for drugs placing the infant at risk for congenitally acquired sexually transmitted diseases such as HIV disease (Fullilove & Fullilove, 1989). All infants born to HIV positive mothers will test positive on the standard Elisa and Western Blot tests. These tests measure antibodies to the HIV virus. By age eighteen months, when infants lose maternal antibodies, about 75 percent of these infants will test negative, a process called seroreversion. In the United States, about 25 percent of infants born to HIV positive mothers without AZT treatment will actually have the virus in their body detectable by Elisa and Western Blot tests after eighteen months of age (Nicholas & Clark, 1994). Originally it was believed the virus' primary site of infection was T-cells in the bloodstream; however, in addition to infecting the bloodstream, the HIV virus directly attacks the nervous system. Subtle neurological changes can be detected even in asymptomatic children.

Drug use during pregnancy--especially cocaine-- also increases the risk for premature labor and low birth weight (Batshaw & Peret, 1992). Children born at or before the 36th week of pregnancy

are considered premature and are at risk for developmental delay. Children born prematurely have twice the incidence of learning and behavioral difficulties (Batshaw & Peret, 1992). The newborn premature infant has difficulty regulating its sleep-wake cycles- she sleeps lightly and takes frequent small naps, cries often, and often feeds poorly, her sucking ability being less developed. Differences in neonatal temperament between full term and preterm infants have also been demonstrated in areas of neonatal irritability and resistance to soothing (Riese, 1987). The premature newborn has difficulty with self regulatory mechanisms which help the newborn adapt to both internal and external stimulation (McGehee & Eckerman, 1983; Stern, 1977). Premature infants-- especially very low birth weight babies (under 3.5 pounds) are at higher risk for blindness and other vision problems, hearing loss, mental retardation, and other handicaps (Batshaw & Perret, 1992).

Parenting styles also influence growth and development. The infant's relationship with a primary caregiver forms the basis for all future relationships. At this stage in development, infants require caregivers who can lovingly and consistently provide them with food when they are hungry, diaper changes when they are uncomfortable, and opportunities for play and one to one interaction. Consistent and nurturing care provide a foundation for trust which fosters positive self esteem and creates a child who is eager to love and learn about the world and share her love and talents with others. Caregivers whose drug use causes them to be preoccupied and inattentive to the infant's needs cannot provide this stability. Individuals who abuse substances may have been sexually, physically, or emotionally abused themselves when they were children. As a result, they could have internalized poor role models for parenting. At the same time, attempts to help the infant, through placement outside the home, can paradoxically cause harm as well. Multiple placements in foster care will further interrupt the child's ability to bond and form stable relationships.

When taking into consideration all these factors which can potentially influence development, it becomes clear that separating cause and effect and making predictions about the child's future potential is almost impossible. A child's innate resiliency interacts with his or her environment in unpredictable ways. What is clear is that children can benefit from sensitivity and attention to

their developmental needs, and parents/caregivers can benefit from education and support in order to help meet their children's developmental needs.

A Transitional Residence

Hudson Cradle, a program funded through the Abandoned Infants Assistance Act, is a transitional residence for infants under the age of two awaiting placement in foster care. The program was conceived in response to the high number of "boarder babies" residing in our local medical center subsequent to the Crack epidemic in the late 1980's. Boarder babies are infants who cannot be safely discharged from the hospital, typically because of substance abuse in the birth family, and therefore must reside in the hospital until another placement arrangement is made. A hospital is not the most suitable place for an infant to live; infants in hospitals are exposed to various pathogens, cannot go outside and enjoy the fresh air, and do not receive the one to one interaction that infants need to develop and thrive. Hudson Cradle's transitional residence was conceived as an alternative placement while infants wait for reunification with their families or placement in foster care. The length of stay goal is two to three months.

In addition to "boarder babies", children under the age of two are also referred from the community. A shortage of foster homes in the state coupled with the epidemic of substance abuse has created a need for placement of children at Hudson Cradle. These children typically have experienced neglect, inconsistent parenting, and inattention to their developmental and medical needs. All children at Hudson Cradle are referred from New Jersey's Division of Youth and Family Services, the state's child welfare agency.

Hudson Cradle is a department of a local hospital, located off-site in a brownstone building which provides a more home-like environment for the infants. The Program is staffed twenty-four hours a day with nurses and infant caregivers who provide direct care to the infants. Every baby is assigned a primary caregiver. In addition to the parent support and teaching which the direct care staff provide, a social worker also works directly with the birth families of the infants. Parent services include a weekly parenting group, health education, referrals for concrete services such

as housing and drug treatment, and home visitation. Supervised parent visitation is provided during visiting hours seven days a week. Foster parents are also integrated into the program, receiving training prior to the infant's discharge to their home and monthly training sessions on various issues including infant development. These trainings are open to all foster parents in the local area. Additionally, a part time developmental specialist is on staff to provide comprehensive developmental assessments to all infant residents.

Developmental Assessment

Formal developmental assessment of an infant includes evaluation of cognitive and motor abilities, clinical observation, and behavioral assessment. At Hudson Cradle, infant development is assessed using primarily the Bayley Scales of Infant Development-Second Edition, Denver-II, and/or Bayley Infant Neurodevelopmental Screener, depending upon conceptual or corrected age at the time of the assessment as well as specific abilities to be evaluated. Infants residing in the transitional home receive an initial developmental evaluation. Follow-up developmental evaluations are administered every two to four months, depending on the infant's length of stay. Assessment and diagnosis is guided by the awareness that infants have their own unique developmental progression in motor, sensory, language, cognitive, affective, and interactive patterns. Further, risk status acts differentially on these areas of development.

In terms of cognitive abilities, the developmental specialist assesses expressive language skills, including: spontaneous vocalizations, imitation, sentence formation, and contingent utterances. Receptive language abilities range from responding to and discriminating certain sounds, to pointing to a doll's body parts. Visual-perceptual skills, (e.g., regarding the examiner's face and tracking a ring through a horizontal, vertical, and circular path), are also examined. Spatial abilities and visual-spatial integration skills include: replacing puzzle pieces, placing cubes in a cup, and building with blocks. Object permanence is also evaluated by hiding various objects. Goal-oriented skills include: pulling a string to adaptively secure a ring, using a rod to attain a toy, and discovering a route on a map. Pre-reading, pre-writing, qualitative reasoning, and interpersonal skills are also evaluated.

An evaluation of motor abilities, including fine and gross motor skills, is also part of the developmental assessment. Fine-motor skills include grasping a pellet or a cube. Gross-motor abilities, (e.g., the capacity to roll, sit, stand, walk and jump), are also evaluated. The presence of certain reflexes are assessed in neonates, including: rooting, moro, palmar and plantar grasp, primary standing and walking, placing reaction, symmetrical tonic neck reflex and Landau reflex.

Clinical observation is another informative assessment tool and is used as a supplement to the more standardized cognitive and motor assessment techniques described above. The caregiver-infant/child relationship is examined in terms of emotional and behavioral responses in both partners and the pattern and style of interaction. The infant's/child's reaction to the environment, such as response to separation or change, as well as attachment patterns, are observed. Another area of assessment is the infant's/child's constitutional or maturational characteristics.

Behavioral assessment is an essential aspect of the overall developmental evaluation. Behavioral assessment includes an evaluation of attention/arousal, orientation/engagement, emotional regulation, motor quality, and capacity to be soothed.

Input from our interdisciplinary staff including registered nurses, a social worker, and infant caregivers, is especially helpful in providing information about any medical, environmental, and family issues. Infant caregivers, who typically spend intensive time periods with the infants, are a particularly valuable source of information regarding infants' sleep-wake cycles and eating patterns, temperamental changes, interaction styles, and developmental issues.

The following case examples illustrate how comprehensive assessment of infants and their families, with appropriate intervention, can impact developmental outcomes.

Case Example #1

Timmy presented with various risk factors including prenatal drug exposure (primarily to alcohol), and environmental, family, and placement issues. Since he resided in Hudson Cradle's transitional home for six months, initial and follow-up developmental evaluations were given, and Timmy's development was tracked during this time. It was also possible to obtain information about Timmy's environment during infancy, family issues, and experiences with his

caregivers through interview data, (obtained by the infant assessor or social worker), direct clinical observation and behavioral assessment.

Timmy was a fourteen month old, Caucasian male admitted to Hudson Cradle after he was brought in to the child welfare agency by the police who had discovered him and his parents in the local park. His parents were having a domestic dispute, and it was noted that the child appeared neglected and dirty, dressed only in a faded woman's tee shirt. The case was known to child welfare; in fact, Timmy's child welfare worker had been trying to locate the family for three months. The mother was evasive as to their living situation and it was believed that they were homeless. Timmy was born full term with a birth weight of five pounds. His urine drug screen at birth was positive for cocaine. His mother acknowledged using alcohol during the pregnancy and also smoked. She received no prenatal care. The delivery was a normal, spontaneous vaginal delivery, complicated by mild preeclampsia. At the time of Timmy's birth his mother was thirty-six years old and had a long history of alcohol abuse. She had three other children in the custody of their fathers.

At fifteen months of age, Timmy was given a comprehensive developmental evaluation, using the Bayley Scales of Infant Development, Second Edition. At the time of testing, Timmy was alert and receptive to the examiner and test materials. His state was calm and regulated. He showed an active interest in the toys and explored them mainly through tactile manipulation and banging. Sustained attentional focus toward one toy was limited, as Timmy was quite vigilant towards his surroundings. Timmy related to the examiner in a friendly manner with much eye contact, smiling, and vocalizations. Developmental test results showed that overall cognitive skills were in the mildly delayed range and overall motor abilities were in the significantly delayed range. In terms of cognitive abilities, Timmy exhibited specific delays in visual-spatial-motor coordination and integration, receptive and expressive language, object permanence, and goal oriented behaviors. It was also noted that Timmy's limited attention span may have impeded his mastery of some test items. In terms of motor development, Timmy exhibited specific delays in gross-motor abilities such as standing, or walking independently. Gross-motor functioning was at the seven month old level. Fine-motor deficits were also observed.

During his stay, Timmy was referred for speech, occupational and physical therapy. He was followed by a primary care physician and his health and immunization needs which had been neglected were now attended to. He also was referred to the neurology clinic for evaluation. A CAT Scan showed mild cortical atrophy.

Since his admission to transitional care, Timmy's primary developmental advances have been in the area of gross motor skills. Three months after his initial assessment, at eighteen months of age, Timmy acquired the ability to stand and walk independently. Tentative on his feet at first, Timmy took obvious pride in his mastery of this new ability to explore his world. Simultaneously, sensitivity to separation from the staff to whom he had become attached was noted. Developmental progress was also noted in terms of fine-motor skills and expressive language, although Timmy's functioning in these areas still lagged behind his same aged peers. In terms of the caregiver-child relationship and interactive patterns, Timmy initiated and enjoyed relating to familiar adults and peers, was playful and flexible. When interacting with his biological parents during visits, Timmy was active and vocal while sitting on his mother's lap, as his father stood nearby. Both parents were somewhat constricted in their interactive

behaviors and affective engagement toward Timmy. Their visits were inconsistent and dropped off considerably over time. Nonetheless, Timmy continued to bid for their involvement and response to him during visits, only to be minimally reciprocated by either parent.

Timmy was sensitive to separations from certain staff, initially becoming anxious, upset and reaching his arms out to be held; however, he was able to quickly reorganize his response and turn his attention to other people or toys in the room. Timmy was, in general, vigilant and sensitive toward his environment. Initially wary of transitions, he soon appeared to be more confident and trusting of the world around him. Sleep-wake cycles and eating patterns were stable and consistent.

Unfortunately Timmy's parents did not comply with the child welfare agency's plan for them to enter alcohol rehabilitation and secure stable housing and, in general, resisted any attempts to engage them in treatment or to assist them in locating stable housing. Although an uncle was explored as a placement option, this did not work out. After six months at Hudson Cradle, Timmy was placed in a foster home and arrangements were made for him to continue his therapy at a local center near his new foster home. Recently, he turned two. He has bonded with his new foster family, and by all reports is doing well. Unfortunately, Timmy's prognosis is guarded. It is unclear whether a permanent living situation can be secured for him, and he has lost contact with his parents, at least temporarily.

Case Example #2

Beverly is a twelve month old girl of African-American and Hispanic descent who was referred to transitional care after being placed in an emergency foster home. Her mother has a long history of substance abuse including heroin, cocaine, and nicotine. Beverly was born prematurely, at 29 weeks gestational age. A urine drug screen was positive for cocaine at birth. Beverly was a very low birth weight baby, weighing one pound eleven ounces at birth. Her case was known to child welfare authorities but had been closed some time after her birth. She has two older siblings residing with the maternal grandmother. At the time of her admission to Hudson Cradle, Beverly's mother had left her in the care of a friend and could not be found. Her father was in jail on domestic violence charges brought by the mother. The friend called child welfare and the child was removed and placed in an emergency foster home. From there she was admitted to Hudson Cradle's transitional residence.

Beverly was given a comprehensive developmental evaluation at 13 months (correcting for prematurity, her age was 11 months) and again at 15 months (corrected age 13 months) using the Bayley Scales of Infant Development, Second Edition, adjusting the test scores for prematurity. During both the initial and follow-up evaluation, Beverly was alert, active, and interactive. Her state was well modulated. She was attentive toward tasks and explored objects through tactile manipulation, banging, and mouthing. She was quiet with few vocalizations, and appeared to take in her surroundings with her large, bright eyes. Results of Beverly's initial developmental evaluation showed that both her mental and motor functioning were in the significantly delayed range. Specifically, Beverly exhibited delays in expressive and receptive language, visual-spatial-motor skills and integration, coordination, goal-oriented and imitative behavior, and gross and fine motor abilities.

At the time of Beverly's initial evaluation, she vocalized different vowel sounds but did not imitate vocalizations or repeat vowel-consonant combinations. She did not selectively listen to familiar words or respond to a spoken request. She sat steadily, but eventually was unable to maintain herself in this upright sitting position. Social interaction was an area of relative strength as Beverly enjoyed games of peek-a-boo. Beverly's tendency to explore objects through relatively less mature modalities, such as mouthing and banging, may have impeded her performance on certain tasks.

Beverly was referred for early intervention services. The early intervention team evaluated her and provided once a week individual and group sessions. She was also referred to a primary care physician who provides her with her immunizations and medical follow-up.

At the time of Beverly's follow-up evaluation, Beverly showed some developmental advances, particularly in gross and fine motor areas, but continued to exhibit overall delays compared to her same-age peers. She learned to sit in a more controlled, independent manner and showed pre-walking skills when guided and supported. Beverly was more vocal, used vowel-consonant combinations and jabbered expressively at the time of her follow-up evaluation. She also responded to spoken requests and listened selectively to familiar words.

In terms of her reaction to environmental changes, Beverly easily adapted to transitions, and separations. Her state was well-modulated and she was able to play alone in her crib when staff was unavailable. Her sleep-wake cycle and eating patterns were consistent and stable. In terms of the caregiver-child relationship and interactive patterns, the following was observed while Beverly was in transitional care. Beverly's biological father was released from jail as charges were dropped against him. He began to visit her on a regular basis. They played quietly together for extended periods.

Beverly's father was attentive, gentle, and loving toward his daughter. She was often observed climbing on him, sitting quietly on his lap, or sharing a toy with him. Beverly's father is pursuing custody. He now resides with his aunt and uncle since his own parents are deceased. He is employed in his uncle's business. Beverly's mother entered drug treatment out of state. She enrolled in an aftercare program and came to visit Beverly once. During Beverly's stay at Hudson Cradle, she relapsed. The child welfare agency's plan is to return Beverly to her father pending his compliance with certain conditions including a psychological evaluation, and aftercare arrangements for Beverly including continuation of early intervention services and visiting nurse services.

This case also illustrates the multifactorial causation of developmental delay in children who are prenatally exposed to drugs, born prematurely, experience inconsistent caregiving, and placement in foster care. Developmental assessment is important in providing measurable developmental outcomes in a manner which is comprehensive and useful. Information about cognitive, social, emotional, and motor development as well as issues such as the present parent child relationship,

the ability of the caregiver to take the child to his appointments, and the special needs of the child, can assist in making decisions about early intervention and child placement.

Integrating Developmental Issues into Programs That Serve Families

The diversity of programs funded by the Abandoned Infants Assistance Act is testimony to the fact that it is possible to serve families in different ways, depending on differing needs and circumstances. Services to high risk families can occur in outreach programs, residential drug treatment programs which provide residential space for children, transitional residences, outpatient drug treatment settings, and others. These programs differ in their staff mix, funding, treatment goals, and target populations. Attention to the children's developmental needs in at-risk families must be an essential component of any program that serves these families.

Case management and linkage to community resources are invaluable in a time of decreasing funding and increasingly complex client needs. At Hudson Cradle, a social worker and nurse case managers refer families to the services which cannot be provided at the facility, and they facilitate information flow between providers, families, facility staff, and child welfare workers. As an example of successful agency linkages, Hudson Cradle has an arrangement with a local early intervention program which is grant funded to provide outreach services. Staff from the early intervention program come to Hudson Cradle and assess and provide treatment to the resident infants.

Parent training and support, including birth and foster parents, should be culturally sensitive and vigilant to the parents' strengths and weaknesses. Staff who provide parent education and who interact with parents on a regular basis need to be in touch with their own biases and feelings about what a "good" parent should be. Attention to the child's developmental needs is not an obvious parenting role for some parents; some parents may not be aware that their child is developmentally delayed or, if they are aware, they may characterize a delay (not walking for

example) as "laziness" or "stubbornness". Birth parents may need to work through feelings of guilt, and foster parents may need to work through feelings of anger.

Ongoing staff development and quality improvement activities are also important program components. Hudson Cradle's staff learn from the developmental specialist and early intervention staff activities which can promote the infant's development, (e.g., game playing, floor time, face-to-face social interaction, story telling, naming body parts during bath time), and providing the opportunity for children to experience different environments. Quality improvement activities include information gathering and self evaluation opportunities which can enrich program services. Whether program services include comprehensive developmental assessment conducted by program staff or whether these services are provided by outside agencies, it is important that developmental assessment not be neglected, as children's future intellectual, psychological, and interpersonal potential can be impeded by issues not addressed at an early age.

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DEVELOPMENTAL OUTCOME OF INFANTS AND YOUNG CHILDREN WITH PRENATAL ALCOHOL- AND DRUG-EXPOSURE

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Background

Despite advances in the identification of infants born with prenatal alcohol and drug exposure (PADE), clinical research addressing the developmental outcome of these children has not been definitive. Researchers have been unable to find a set of behaviors or learning disabilities that clearly distinguishes children with prenatal exposure from other children with different learning styles or problems. The heterogeneous nature of the population, including regional and cultural differences within the U.S., make generalization of findings reported as a consequence of exposure problematic.

The answer to the developmental variation in children with PADE lies in the interaction of environmental/psychosocial, developmental/behavioral, and medical/biologic factors rather than in the initial exposure itself. Multiple risk factors have a cumulative and transactional effect on development, but certain combinations of risk may be particularly damaging (Aylward, 1992). These risk factors make it difficult to determine the impact of isolated drugs on the developing fetus and their contribution to later development.

Potential Biological Risk from Prenatal Exposure

Accurate determination of prenatal exposure to specific drugs requires the development of a simple, sensitive, and specific test (Volpe, 1992). Currently, exposure is often ascertained by testing maternal and neonatal urine for a drug type and its metabolites and/or by interviewing the mother. Zuckerman and his co-workers (1989) have stressed the importance of using both approaches. From their study of 1,226 mothers, they found that on the basis of interview alone, 24 percent of cocaine exposed infants would have been missed, and from urinalysis or toxicology

screening alone 47 percent of the exposed infants would have been missed. Toxicology screening by itself only provides evidence of recent exposure and the duration of exposure throughout the pregnancy cannot be determined. In addition, the method of drug use, the quantity used each time and the frequency of use are all difficult to quantify and relate with assurance to the outcome of the child. Further complicating the task of researching individual effects are differing maternal metabolic systems, varied prenatal care, maternal nutrition, and birth order (MacDonald, 1992).

Potential Interactions of Biologic and Environmental Risks

Environmental quality has been considered in conjunction with low birth weight and severity of perinatal complications as a determinant of developmental outcome (McGauhey, Starfield, Alexander, & Ensminger, 1991; Werner, Simonian, Bierman, & French, 1967). In these studies the children with both poor environments and less optimal neonatal status had the worst long-term outlook. A more recent study looking at the efficacy of early intervention with preterm infants up to the age of three years (Brooks-Gunn, Liaw, & Klebanov, 1992) found that subjects who had higher birth weights benefited more from the intervention than those who weighed less at birth. Other studies have found that maternal education and socio-economic status (SES) were most predictive of development up to age three in children with heavier birth weights (Korner, Stevenson, Kraemer, Spiker, Scott, Constantinou, & Dimiceli, 1993); but for infants weighing less than 1,500 grams at birth, a neonatal medical risk index was at least as predictive as the sociodemographic variables. Several investigators have underlined the importance of evaluating the interactive effects on outcome and the difficulty in documenting them (McCall, 1991; Wachs, 1991; Sameroff, Feifer, Barcas, Zax, & Greenspan, 1987).

Implications of Biologic and Environmental Risks on Developmental Outcome

Bendeersky and Lewis (1994) concluded that a family risk measure comprised of social support, parent-child interaction, stressful events, and organization of the environment was as powerful a predictor of overall two-year outcome for their group of 175 preterm children as were measures of early medical compromise. In addition, they found that specific developmental functions are affected differentially by the rearing environment. When the effect of medical status was removed, environmental factors accounted for much of the variance in Bayley Mental Development Index

(MDI) scores and language ability, but very little of the variance in motor scores. This pattern of relation suggests that the environment has the greatest impact on more cognitive skills as opposed to abilities that are predominantly motoric. However, biologic factors explained the greatest variance in the motor skills as measured by the Bayley Psychomotor Development Index (PDI).

This relationship between environmental and biologic influences on development is best illustrated by the neurobehavioral abnormalities seen in newborns affected by PADE. The early hypertonia or increased muscle tone that secondarily affects motor function resolves itself by six to nine months of age in the majority of children, despite environmental variables. What appears to become compromised through inadequate environmental interactions are language competence and a motivation to learn.

Research literature and media have highlighted poorer developmental outcomes among children with PADE. A substantial number of these children test within the low borderline normal range throughout early childhood but then problems emerge in the context of academic performance. Lahey (1990) reported that when children from poverty are given tasks that stress the use of their language systems, their limitations become evident. It appears difficult for some children with PADE, along with other children from impoverished backgrounds (Fazio, Naremore, & Connell, 1996), to acculturate to the academic environment. A number of these children have family histories of educational difficulties or families who do not feel comfortable with the public school system and thus may not consider education a premium. In those instances, future worries about a child's school attendance and motivation prevail.

Los Pasos Program

The increased incidence of prenatal exposure and the social and environmental stresses that provide the backdrop for so many of our country's children living in poverty requires that intervention teams use more functional strategies with young children and their families to encourage normative development and educational adaptation. Drawing from social support, early intervention and health care delivery systems, programs such as the Los Pasos Program, funded

under the Abandoned Infants Act (AIA), have attempted to demonstrate approaches directed at families and children affected by substance abuse.

The Los Pasos Program in Albuquerque, New Mexico, initially received AIA funding in 1990, under the direction of Dr. Andrew Hsi, a pediatrician at the University of New Mexico Children's Hospital, who had recognized the need for comprehensive medical, social, and early education services for infants and families affected by substance abuse. The Los Pasos effort has been towards maintaining family permanency while ensuring the safety and developmental needs of identified children from infancy to three years of age. Over the course of six years, the Los Pasos interdisciplinary team has served over 900 newborns primarily born at the Children's Hospital in addition to referrals from other hospital nurseries in Albuquerque and around the State of New Mexico. Additionally, an adjunct project to aid entry into Head Start programs was initiated in the Fall of 1994, to address the needs of children with early mild developmental delays and family histories which may impact later academic performance.

The Los Pasos Team has found the challenges and needs presented by children with PADE unique and multifaceted, but similar to other children at risk. Some of these shared attributes that make it difficult to isolate the group on the basis of exposure are: variable attention and arousal, neuromotor abnormalities, labile temperaments, difficulties with social communication and self regulatory patterns, and limited object play or representational play patterns. Isolating the biological effects of prenatal exposure on developmental outcome from social, educational, and cultural factors has proven nearly impossible.

The development of children with PADE in the Los Pasos Program has involved understanding and working within a systems context in which the child comprises only one element of a larger and more complex system. This chapter will review the trends reported from a five-year study of the Los Pasos Program, the developmental course of 30 children from birth through Head Start enrollment (3 to 4 years of age), the implications for intervention, and future directions.

Trends Reported from the Los Pasos Program

The trends of the population served by the Los Pasos Program come from its Five Year Evaluation. Infants and their families included in the evaluation were identified for the Program at the time of delivery through maternal interview and toxicology screenings of both the newborn and mother. Participation in the program is voluntary. Data collected from 700 families over the course of the five year study have been compared to a matched substance-free group. A sample of the data relevant to developmental outcome will be reviewed.

Status of Mother's Drug Use During Pregnancy

Smoking during pregnancy is harmful to the developing fetus and can result in smaller infants, yet cigarette smoking appears to be on the rise. Los Pasos mothers reported more tobacco use than mothers in the comparison group. The trend over the course of five years of Los Pasos women who reported smoking regularly rose from 51.3 percent in the first year to 71.8 percent by the fifth year. Given the known risks posed by exposure to tobacco, infants in the Los Pasos Program have an additional causal agent for developmental problems.

A substantial number of Los Pasos mothers used cocaine, cannabis, or alcohol as their predominant drug of choice (66.6 percent) although polydrug use was the norm. Of the opiates, heroin use accounted for 9.7 percent of the population with an additional 6.8 percent of the women receiving methadone during pregnancy. Although the mean use of amphetamines was 5.4 percent of the total pregnancies, an increase in use of amphetamines was observed from the second to the fifth years, rising from 2.4 percent to 14.3 percent.

Health Status of Mothers

Los Pasos women had lower levels of prenatal care than women in the comparison group. For the Los Pasos group, 40 percent were considered to have medium to high levels of prenatal care based on standards developed by the New Mexico Department of Health (low= less than 3 visits; medium= between 3-8 visits; high = 8+ visits). In contrast 66 percent of the women in the

comparison group and 88 percent of all women delivering babies in Albuquerque had medium to high levels of care. For the first five years of the program, medium to high level prenatal care rates reportedly increased for the Los Pasos women (approximately 35 percent in the first year rising to nearly 50 percent in the fourth). Women in the comparison group had steadily increasing levels of care over the five years. Overall, the Los Pasos mothers received significantly fewer prenatal visits (mean 5.1 visits) than comparison mothers (mean 9.2 visits).

In other indicators of health status, women in the Los Pasos Program gained significantly less weight during pregnancy (mean weight gain 29.65 pounds) than women in the comparison group (mean weight gain 32.15 pounds). In addition, a low prevalence of positive HIV tests was documented among the Los Pasos mothers (0.5 percent) and none in the comparison group.

Status of Infants

There was a significant difference between the mean birth weight of Los Pasos infants (2,787 grams) and infants in the comparison group (3,139 grams). The five year trend showed a decreasing birth weight for infants in the Los Pasos Program. Nearly 25 percent of the infants had a designation of low birth weight in contrast to 12.5 percent of the comparison group. Babies in the Los Pasos Program had a significantly smaller mean head circumference and length and had a mean gestational age of 37.66 weeks compared to 38.42 weeks for the comparison group. The mean length of hospital stay for the Los Pasos infants was 10.57 days compared to 4.32 days for the comparison.

Many of the babies with conditions affecting labor and delivery or diagnosed as conditions or anomalies required intensive care. Infants in the Los Pasos group admitted to the intensive care unit had significantly lower weight, head size, and length and were considered small for gestational age. They required longer intensive care unit and hospital stays.

Social and Environmental Status

The mean age (26 years) and educational attainment level (11th grade) of the Los Pasos mothers was similar to the comparison group. Significantly less of the Los Pasos mothers were married (21.2 percent) compared to 55.3 percent of the other mothers, and 23.5 percent of the comparison mothers were employed compared to 3.5 percent of the Los Pasos group. The majority of Los Pasos mothers received public assistance and a number had histories of transient living conditions.

Most of the children remained in the physical and legal custody of the mother (62.9 percent), 3.7 percent remained in the physical but not legal custody of the mother, and 12 percent lived in the custody of a member of the mother's kinship network. By comparison, fewer of the older siblings (53.9 percent) remained in the mother's custody.

Domestic violence, physical and sexual abuse was reported by 142 of 382 Los Pasos women. The remainder of the women in the five year study did not have these issues explored.

Developmental Evaluations

When the Los Pasos Project first began service delivery, the Bayley Scales of Infant Development (BSID) was chosen as a nationally recognized standardized instrument to assess and monitor the current developmental functioning of infants and children. The primary value of the test was in diagnosing developmental delay and planning intervention strategies. The majority of the children (73.3 percent) received mental development index (MDI) and psychomotor development index (PDI) scores within the normal performance range during the first year of life. The early hypertonia or increased muscle tone apparent in early infancy that secondarily affects motor function resolved itself by six to nine months of age in the majority of children.

When scores differed between the two index scores, more children scored within the normal limits on the PDI with delays on the MDI. A number of children had developmental scores that decreased from their first to their last assessment, especially as the children became older and

more language items were included. In addition, more children showed delays when the stability of their living situation worsened; conversely, with better home stability, higher percentages of children had normal BSID scores.

In regard to the developmental findings of older children, a sample of Los Pasos children that have been followed from delivery through enrollment in Head Start programs will now be reviewed.

Sample Study of 30 Children - Birth Through Head Start

Social History

The social histories of 30 Los Pasos children included for Head Start enrollment were recorded from social work notations in the medical records. Eight notations reported continued drug use by the mother. There were four foster home and four adoptive home placements. Nineteen children lived with their biological mothers and four lived with a grandmother. Of the children living with their mothers, fifteen had single parents. Only two of the children were third- and fourth-born and living in the same household with their siblings.

The structure and family into which a child is born affects the kind of language and stimulation the child receives. Discord and discontinuity in relationships can affect not only the cognitive and linguistic competence but also the socioemotional and behavioral development of a child (Belsky & Vondra, 1989). The number of single parents (15) in this sample was striking along with the number of children (7) who changed their caregiving situation at least once over three years. Four of the single mothers were in relationships with reported physical abuse. Of those single parents whose children maintained normative scores on sequential assessments, more mothers reported reading and talking to their children in a conversational manner.

While the sample studied cannot give a comprehensive view of the entire social environment confronting children with prenatal exposure, the factors identified can have potential impact on development.

Medical History

The medical status of the group eligible for Head Start entry included prenatal exposure to alcohol and other drugs. Several medical conditions appeared frequently in the medical records attained for the sample children. They included: otitis media (50.8 percent), skin conditions and infections (13.6 percent), head circumference below the 10th percentile (13 percent), and failure to thrive and related child abuse (8.9 percent). In addition, 27 percent of the children were born full-term and considered small for gestational age (SGA - weighing less than 90 percent of other infants of the same gestational age).

Children born to drug-abusing families have an increased risk for illnesses and infections because of poor parenting skills, nutritional deficiencies, and a higher-than-normal incidence of parental smoking behavior. Seventeen of the children lived in homes where regular smoking occurred. Passive smoke is another example of how an effect of prenatal drug exposure can be magnified in the postnatal period because recurrent ear infections during the first two years of life can contribute to delays in speech and language and later learning disabilities (Thal & Bates, 1990). Nine of the sample children had three or more ear infections diagnosed during the first year of life. Language delays, learning disabilities, and attention deficits are also common in SGA children (Allen, 1992).

Exposure histories of the sample children included the following:

	PRIMARY	SECONDARY	TERTIARY	QUATERNARY
Heroin/Methadone	9	-	-	-
Cocaine	4	2	1	-
Marijuana	3	2	2	-
Alcohol	2	5	-	1
Amphetamine	2	-	-	-
Benzodiazepine	-	-	-	1

Based on histories of substance use during pregnancy, polysubstance use was the norm among mothers of sample children. The above table indicates drug use by order of client preference among polydrug users.

Developmental History

Birth to 13 months

At birth, the 30 children in the cohort study were given the Neonatal Behavioral Assessment Scale (Brazelton, 1973) and described as having state regulation problems while in the newborn nursery. There were problems noted with jitteriness, tremors, mottling of the skin, circulation, crying, and sleep patterns. Parents were given training on reading a baby's emotional cues and on ways of comforting their babies. Once discharged from the hospital, a home health nurse was sent to the home once a week to check on weight gain and maternal/child bonding.

A home visit was scheduled when the baby was between four and five months of age and the Bayley Scales of Infant Development (BSID) were administered. The children had scores within the normal performance range on the Mental Development Index (MDI) and the Psychomotor Development Index (PDI), although motor performance was, for some of the children, compromised due to unresolved hypertonicity which interfered with motor planning (the execution of an idea). In a few other cases, motor development appeared precocious due to the

high tone affecting early sitting, crawling, and head righting positions. Interventions for the caregivers included infant massage techniques and ways to interact and play with their babies.

All 30 children received a full BSID at close to one year of age with the mean age being 13.1 months. None of the children had scores of 84 or less (one standard deviation below the mean). When other children with PADE, six to ten months (mean age eight months, 20 days) were compared to the sample children, the mean MDI scores were 108 and 107 respectively and the mean PDI scores were 109 and Table 1 captures the early scores on the BSID.

Table 1

**Mental Development Index and Psychomotor Development Index Scores
on the BSID During the First 13 Months of Life**

Age	MDI	Mean Age Equivalent	PDI	Age Equivalent	Classification
4-5 mos.	108	4-5 mos.	106	4-5 mos.	wnl*
8.7 mos.	108	8-9 mos.	109	8-9 mos.	wnl*
13.1 mos.	107	12-13-mos.	102	12-13-mos.	wnl*

*within normal limits

Although the children scored within the normal range on the BSID, clinical observations and caregiver report showed that 72 percent of the children had limited babbling and vocal play and 30 percent were characterized as having very active or “busy” behaviors. Of the 30 percent with active behaviors, parents reported problems with napping and/or falling asleep at night, and/or problems with mealtimes.

18 to 23 months

Between the ages of 18-23 months (mean age of 20 months) the cohort was given a battery of standardized tests to evaluate medical, environmental, and developmental risk factors impacting each child. The multivariate assessment battery was designed for dissertation research by Dr. Jane Clarke to determine:

- If a battery of multivariate assessment techniques could classify developmental differences between this group and a matched non-exposed control group; and
- If any differences existed between the two groups on measures of language and play.

The battery assessed head circumference, SES, family risk factors, behavior, overall development, language, and play (see Table 2 for test names and references). The assessment procedure involved a medical evaluation, direct testing by an examiner, observation, and parental report.

Table 2
Assessment Components

	SES-COMP ¹	DOCS ²			PLS-3 ³	SPT ⁴	HC ⁵
		DC	PSSC	ABC			
Overall Development		X					
Language		X				X	X
Cognition		X					
Fine/Gross Motor		X					
Child Adaptability					X		
Play		X				X	X
Sociability		X				X	X
Parent-Child Interaction		X	X	X			
Parental Stress				X			
Parental Support	X		X				
Environmental Impact	X		X				
Growth							X

¹SES-COMP: Socioeconomic Status – Composite Index.

²DOCS: Developmental Observation Checklist System. The DOCS includes: DC (Developmental Checklist); PSSC (Parental Stress and Support Checklist); and ABC (Adjustment Behavior Checklist).

³PLS-3: Preschool Language Scale – 3.

⁴SPT: Symbolic Play Test.

⁵HC: Head Circumference, a proxy measure of brain growth.

Relationships among the measures of risk factors were compared for the children with PADE and the nonexposed group. Measurements from the medical evaluation of the children and scores from the various instruments became the predictor variables for statistical analyses. Raw scores for all measures were used for analyses except for the SPT (Symbolic Play Test) which yielded an age equivalency score.

The Preschool Language Scale-3, the Developmental Checklist (DC) from the Developmental Observation Checklist System, and the SPT showed the greatest amount of differences between groups of children with and without PADE. The delays of the group with PADE in auditory comprehension, expressive communication, and representational play classified them apart from the control group. In addition, their language delays adversely affected their overall development, which was manifested in the Developmental Checklist scores.

The children in this study demonstrated delayed rather than deviant language development. For example, the children were more likely to fall into the 14 to 15 month age range where a child may not yet say a whole word but instead may utter only the initial sound such as “ba” for “ball”, “ca” for “car”. The number of audible words that most children were able to speak was considerably less (an average of eight words) than that expected of an 18-23 month old. In addition, a limited consonantal repertoire used in sound making was evidenced, along with limited use of jargon.

In its purest form, play is defined as imitation, imagination, and transformation. Teachers who have examined what children do when they play, see it as a special activity with features that set it apart from other behaviors. Such features include self-directed interest, active engagement, and experimentation with ideas about the world and relationships with peers and family. They make longer utterances and use more varied vocabulary when they are playing.

For most of the PADE group, play was characterized by throwing, banging, putting toys in containers and dumping them out, and picking up and putting down toys. Often there was not

sustained combining of toys, early fantasy play, or curious exploration. However, modeling conditions served to increase pretend behavior and raise the developmental level of play in both groups of toddlers. According to Feurstein (1979), a particularly important facilitating condition for young children is mediated learning, which involves an experienced adult who “mediates” between the child and the world by “framing, selecting, focusing, and feeding back environmental experiences” so as to create “appropriate learning sets and habits” (p.35). However, even with the social mediation, the PADE group tended to lag behind the control group.

The scores on the Adjustment Behavior Checklist (ABC) did not yield significant differences between the PADE and control groups. However, the children with the lowest ABC scores (children who are perceived by their parents as showing inappropriate behaviors that are difficult to handle) were often accompanied by low Parent Stress and Support Checklist (PSSC) scores (a family operating under adverse conditions) as well as low DC scores. Some children with PADE may not be able to verbalize or communicate their needs, wants, and fears in a meaningful way, but rather may tend to express them through behaviors, such as whining, banging, stomping, and shouting. Families under stress may not be able to respond to the emotional and developmental needs of their children, which may result in adverse behaviors.

Additionally, children who live with aggression, may become aggressive. For example, among the study children, those who displayed aggression were most often found to have families with more restrictive caregivers. They also had siblings who retaliated aggressively and mothers who reported more physical aggression between themselves and their partners.

On the PSSC, 75 percent of the PADE group's mothers reported that they were depressed as opposed to 58 percent of the control group. Depressed mothers of infants fail to use the exaggerated intonation contours characteristic of baby-talk and are slower to respond to infant vocalizations than are mothers not experiencing depression (Bettes, 1988). In addition, Nelson (1973) reported that mothers also differ in the extent to which they ask questions versus give demands, as well as in the extent to which they discuss objects of interest versus talking about

personal matters. Several investigators have supported the hypothesis that a mother's use of decontextualized/informational language to their children at ages two and three is related to higher literacy achievement (Norton, 1996; Snow, 1991).

It should be noted that although delays were documented between the groups, the magnitude of the delay would not qualify them for services under the guidelines for eligibility which were operational in the State of New Mexico at that time; nor were they warranted. Only in cases of moderate to significant delays were home-based or center-based services able to be accessed.

3 to 4 years

At three years of age, the children were tested while they attended the Head Start programs. The average age tested was three years five months, and the following scores were attained using the Test of Early Language Development Second Edition (TELD) (Hresko, Reid, & Hammill, 1991).

Test of Early Language Results:

Raw Score	Language Quotient	Language Age	Classification
20	90	2 yrs. 10 mos.	90-110

Although the group as a whole had a mean score within the low borderline normal range, the delays of eight children (27 percent) had become significant enough to be referred to the public school Child Find program to receive speech/language services and 30 percent demonstrated mild delays which could affect later academic performance.

Areas of difference at this age were in the following language areas:

- Phonology
 - developmental delay in articulation acquisition
 - poor intelligibility of speech
 - problems in selective attention
 - problems in sustained auditory attention

- Semantics
 - limited vocabulary
 - poor discourse skills
 - difficulty with verbal directions
- Syntax
 - overuse of short basic sentences
 - limited variety of sentence forms
 - inability to sequence information or retell a story
- Pragmatics
 - inability to follow turntaking routines
 - overdependence on performatives

The Head Start teachers completed the Developmental Checklist of the DOCS based upon classroom observations of the performance of approximately half of the group enrolled through Los Pasos. The mean scores and their interpretation are provided below:

	Raw Score	Standard Score	Percentile Rank	Age Equivalent In Months	Classification
Language	131	87	19	29	Below average
Cognition	165	89	35	30	Borderline average
Motor	153	97	42	33	Average
Social	123	90	25	31	Average

Two of the children were difficult to maintain in the Head Start setting due to behavioral issues. One was a child in foster care who was placed in day care at 7:00 a.m. each morning and then bused to the Head Start Center for the afternoon session, bused back to day care, and then picked up by her foster mother at 6:00 p.m. daily. Her emotional needs made her very demanding for the teachers and she would often throw things and engage in tantrumming behaviors. An adoptive placement outside of the Albuquerque area was finally secured for this child.

The second child, who had been adopted by a paternal aunt, was difficult to manage in the classroom because he was constantly on the go. He would often push the other children and cry to the teacher claiming that they had hurt him. In addition, he would not stay in his seat on the bus, undoing a restraint and running up the aisles. The parent supported her son saying that the other children were picking on him, and stated that he was “as good as gold” at home. The Los Pasos social worker attempted to mediate differences between the Head Start and the parent, but in the end, the parent withdrew her son due to teacher negativity.

Difficulty with social interactions is often reported for children with PADE and is common with children with developmental language impairments. Trauner, Ballantyne, Chase, and Tallal (1993) suggested from their study of children with language impairments that the observed social dysfunction is due to a difficulty in understanding or communicating the affective nuances of language and leads to misinterpretation of social cues. The deficits appeared to be modality specific, that is, the language impaired children had difficulty with comprehension and spontaneous expression of affective intent in the auditory (voice), but not the visual (facial expression) modality. Children with PADE, who have depressed mothers, have the potential to have affective deficits in both modalities.

Having reviewed the developmental course of a sample of Los Pasos children, it is clear that some of these children are displaying risk indicators of later reading and learning problems. Chasnoff and his co-workers (personal communication, 1996) are reporting a greater number of primarily cocaine exposed children from their original study group, requiring referrals to Special Education at six and seven years of age compared to their control group.

In order to determine intervention entry points, assessment of early development in children birth through four years of age should involve transdisciplinary team members, caregivers, and families, and should include:

- current knowledge of developmental phases or stages;
- family history of speech/language delays and their level of stress, support, and risk;
- infant’s vocal communication, sound production, and communicative intent;

- emerging social, affective, cognitive, and linguistic domains through play;
- communicative interactions between caregiver and child;
- child's early coping deficiencies and strengths; and
- child's medical history of otitis media effusion.

Despite the developmental issues that have been illustrated, children with PADE represent a heterogeneous group whose future development is difficult to predict (Greenspan, 1995). What is important for intervention is the quality of caregiving practices and early experiences that are known to enhance the development of all children. It is best to attain implications for intervention from natural processes.

Implications for Intervention

Despite the small number of this sample, the concluding experience has been that the developmental outcome of children with PADE, including almost every other biological risk condition, is dependent on family variables. That is, it was not so much what was going on within the child but rather what was going on within the family that determined the developmental skill level of each child. The key is to intervene early and robustly (Greenspan, 1995) when the risks aggregate, and to focus on relationships. A discussion of areas for intervention will include caregiving practices, the environment, language, and, finally, coping and resiliency.

Caregiving Practices

Early experiences can shape and alter the developing child. The interactions and transactions children have with their caregivers and family as well as the influence of wider societal factors influences their language competency (Garcia Coll, 1990; Walker, Greenwood, Hart, & Carta, 1994). The early relationships and learning opportunities offered in the home and community establish much of what may be learned, how and when it will be taught, and the rate of learning (Heath, 1989).

Many studies of individual child-caregiver dyads demonstrate the interactive, bi-directional nature of early communication. The high incidence of language delay accompanying disordered child-caregiver relationships, suggests that when the appropriate threshold of social support is unavailable, the child's capacity for language acquisition is affected (McCune, 1992). If a caregiver is ineffective in reading a child's emotional and communicative cues, or is inconsistent in response to their communicative attempts, important language learning opportunities are missed.

The best prevention of language delays is to facilitate early communication by working on the relationship between the caregiver and the child. Greenspan (1992) defines the 'caregiver' as the person or persons familiar with the child and capable of providing the most consistent care to assure security. In cases of shared custody, this may include a team of caregivers who receive the same coaching to benefit this consistency.

Environment

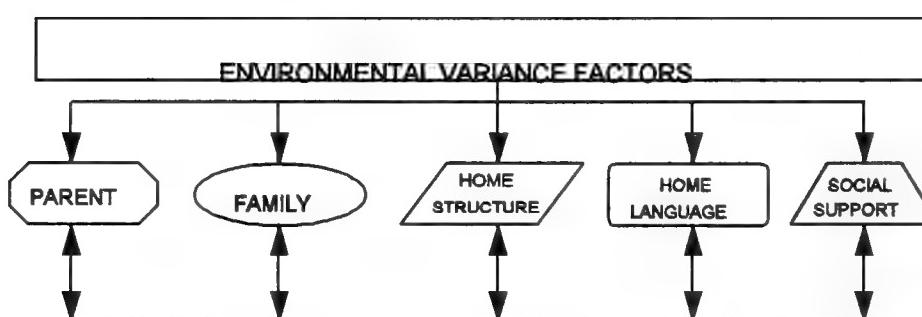
Environmental conditions that make perception of speech more difficult (e.g., living in a crowded, noisy area) or that promote reliance on a more primitive but effective form of communication, such as pointing, whining, and grunting (Whitehurst, Fischell, Arnold, & Lonigan, 1992) constrain language development. Inadequate language learning results from too little adult input, from too many commands or directives and not enough good questions, comments, and implicit corrections. Studies of vocal interaction in low socio-economic status (SES) families suggest low rates of conversation and limited vocal repertoires that are not reflected in structural (grammatical) deficiencies but in vocabulary usage (Hart & Risley, 1992). Disadvantaged families reportedly play fewer games that are conducive to early language learning and typically ask their children less often for language.

The environment in which a child is raised has long been recognized as crucial to determining developmental outcome. The environment can be viewed as a group of interacting variables which can affect a child's development (see Figure 1). For example, the quality of mother-child interactions or number of didactic activities in the home, has been shown to relate to early child

development. These in turn may be affected by the amount of stress in the household, the SES of the family, and how much social support is available to buffer the stresses.

It is important to look at the communicative style of the home environment, but intervening to change caregiving practices requires sensitivity. Dixon (1994) advises that we meet caregivers at their level and try to influence their interest and engagement. Solution Focused Brief Intervention Techniques are useful in affirming the strengths of caregivers to meet the needs of their children. This model, which helps caregivers develop skills that come from solutions caregivers identify as useful to their situation, has been very effective when working with substance abusing families.

Figure 1
Organizational Chart



PARENT	FAMILY	HOME STRUCTURE	HOME LANGUAGE	SOCIAL SUPPORT
Single vs. two parents	Number of Family Members	Organization	Amount of Language	Marital Functioning
Stress Level	Birth Order of Child	Crowding	Complexity	Relatives
Education Level	Violence or Abuse	Didactic Activities	Horizontal vs. Vertical	Community Agencies
Occupation	SES Status	Noise Level	Directive vs. Interactive	Friends or Professionals
Mental Health	Public Assistance			Religious

Language

Recorla (1989) has identified toddlers as late talkers if they have less than a 50-word productive vocabulary at two or no multi-word combinations. Follow-up studies indicate that more than half of the toddlers identified as late talkers at two fail to catch up to their peers by age three. For children prenatally drug exposed and from unstable environments, the chances for catch up may be more difficult without timely intervention.

Some segments of the population have disproportionately high prevalence rates for language delays. Cantwell and Baker (1989) identified six high risk groups. Four of these groups when coupled with prenatal exposure have significance for our population. The four high risk groups include children with:

- Otitis Media. Early recurrent otitis media seems to be associated with later language and learning problems (Teele, Klein, & Rosner, 1990). Children living in impoverished home situations or in homes where smoking is prevalent have higher incidence of otitis media.
- Neurological Involvement. Neurological problems, which include cerebral palsy, apraxia, and attention deficit disorder, produce conditions that range from quite obvious to quite subtle and can affect critical periods for language processing and production.
- Learning Disabilities. These children evidence learning problems that are associated with auditory perceptual difficulties, speech sound discrimination, auditory memory, and dyslexia. These children may display impulsive behaviors because of problems with central auditory processing skills which are often mistaken for Attention Deficit Disorders. In addition children with language/learning impairments have a high incidence of psychiatric diagnoses observed in problems such as social withdrawal and difficulty with social interactions (Cantwell & Baker, 1989).
- Psychosocial Deprivation. Psychosocial deprivation or understimulation in the home primarily affects vocabulary development, discourse skills, and language for self-regulation. It may accompany clinical syndromes such as ‘failure to thrive’ that seems to occur in combination with sparse attention to feeding behaviors.

Even if a child does appear to catch up in language development, other interrelated skills may be negatively affected by its slow development. For example, delayed lexical development may affect metalinguistic knowledge (word awareness and phonemic segmentation) that is involved in literacy development; social-emotional development may be compromised; caregiver-child relations may be negatively impacted; and symbolic play skills less representational (Weisner, Murray-Brand, & Miller, 1994).

Children prenatally drug-exposed with slow language development often have a delay in symbolic play skills. There appears to be a certain relationship between symbolic play skills and vocabulary level. Thal and Tobias (1994) suggest that “late talkers appear to have difficulty using their symbolic capacity spontaneously and flexibly and in situations that require more abstract applications of that symbolic ability” (p. 167). Slow expressive language development may impact the retrieval of stored symbolic representations. In order to help children retrieve stored symbolic representations, mediated learning has proven useful. According to Feuerstein (1979) mediated learning involves an experienced adult who “mediates” between the child and the world by “framing, selecting, focusing, and feeding back environmental experiences” so as to create “appropriate learning sets and habits” (p. 35).

Coping and Resiliency

Coping is the process of making adaptations to meet personal needs and to respond to the demands of the environment (Zeitlin & Williamson, 1994). The more effectively children cope with the demands of daily life and the environment, the more effectively they learn. Effective coping facilitates the acquisition of developmental skills.

Children who are delayed tend to be less effective in their coping behavior. Zeitlin and Williamson (1994) identify the following coping attributes as areas of particular vulnerability for many children with delays or regulatory problems: self initiation, flexibility, independent problem-solving, generalization of learning, management of change and transitions, social reciprocity, and

regulation of mood and affect. These attributes may indicate that children are less resilient to the stresses of daily living, but does not imply that the mechanisms for coping are immutable.

Until children learn to cope or regulate their behavior, they may have limited language skills and exhibit behaviors which have negative outcomes (e.g., temper tantrums, withdrawal). Conversely, a child's limited vocabulary and expressive abilities may contribute to the aggressive and disruptive behaviors often reported in children with PADE.

Conclusions and Future Directions

This chapter reviewed the variables affecting the developmental outcome of children in the Los Pasos Program with implications for intervention. The variables affecting the developmental progress of children with PADE who are at risk for language and learning problems require the coordination of social, educational and health care support services. The resources included in Table 3 incorporate the intervention components discussed above and target the developmental needs of the prenatally drug-exposed child.

Table 3
Creating Change Through Intervention

RESOURCE(S)	DESCRIPTION
Brief Solution-Focused Family Therapy (Berg, 1994; de Shazer, 1991)	A guide to developing parenting skills that come from solutions parents identify as useful to their situation.
Hanen Parent Program (Watson, 1993)	A family focused approach to language intervention with young children which addresses: <ul style="list-style-type: none">• importance of caregiver's participation in the intervention process• the need to provide services to families as early as possible. Can be used with day care providers, foster parents, and/or extended family.

RESOURCE(S)	DESCRIPTION
It Takes Two to Talk (Manolson, 1992)	Three Hanen Centre publications for caregivers and child-care providers of children who are at risk or who are already identified as language delayed.
You and Your Baby: Building Communication (Girolametto & Ushycky, 1989)	
You Make the Difference (Manolson, Ward & Dodington, 1995)	
Transdisciplinary Play-Based Intervention (Linder, 1993)	The transdisciplinary play-based intervention is a natural extension of TPBA and is effective for children from infancy to six years of age. It is designed to provide guidelines for caregivers and other facilitating adults.
Coping in Young Children: Early Intervention Practices to Enhance Adaptive Behavior and Resilience (Zeitlin & Williamson, 1994)	Intervention is directed toward increasing the effectiveness of a child's transactions with the environment. It is targeted for children who have limited coping abilities or who live in high stress environments to build on strengths to foster resiliency.
Family-Centered Early Intervention for Communication Disorders: Prevention and Treatment (Donahue-Kilburg, 1992)	Provides a useful basis for family-centered intervention that emphasizes the role of affect and human relationships in language development.
Infancy and Early Childhood (Greenspan, 1992)	A model of the psychotherapeutic and preventative intervention process which addresses the developing child, child/caregiver interactions, and family patterns.
Infant Massage Training	A technique that promotes bonding between the infant and caregiver and promotes early communication development by training caregiver to read emotionally communicative cues.

The normal variation in development during the first years of life is sizeable and requires conservatism when discussing the prognosis of an individual child. In addition, the developmental outcome of children affected by PADE remains unclear, yet there are profiles of children with delays that require early attention due to multiple risk factors. The notions of a “wait and see” attitude and a general “catch up” in preschool children and beyond are questionable as the risks aggregate for the prenatally drug-exposed child. The gamble is in underestimating the effects of cumulative risk factors until it is too late to intervene successfully.

In the Los Pasos Program, as illustrated by a sample of 30 children, there have been a number of delays in language and language related areas. It has been difficult to account for delays on the basis of initial drug exposure. Developmental outcome depends also on environmental factors,

including those related to socioeconomic status. In effect, as the drug-exposed child gets older, isolating the effects of biological stress from social, educational, medical as well as cultural factors is not possible (Kopp & Kaler, 1989). What becomes more crucial is not the identification of the drugs prenatally ingested; rather, what can be done to overcome developmental delays that are identified at an early age.

The findings reported from the BSID scores attained from early assessments of the Los Pasos children, may have been affected by early standardization data. In the Fall of 1994, the Los Pasos Program was required by state standards to adopt the revised Bayley Scales of Infant Development (BSID-II). A few studies have addressed the issue of equivalence of the BSID-II with the earlier BSID. For example, the BSID-II and the BSID were administered by the test authors in counterbalanced order to a sample of 200 children aged 1-42 months (mean=15.51, standard deviation=10.13). A comparison of the mean MDI and PDI scores showed that the BSID-II MDI score is approximately 12 points lower than the BSID MDI score; and, that the BSID-II PDI score is approximately seven points lower than the BSID PDI score. In essence, the difference between the BSID-II and BSID translates into a child needing a higher raw score on the BSID-II to get the same index score s/he would have obtained on the BSID suggesting that children are performing better now than when the standardization data for the BSID were collected. As a consequence, less children scored within the normal range on the BSID-II (52.8 percent) from the time the revised instrument was introduced.

As the program proceeded and more became known regarding children with PADE and their development, the shortcomings of adopting a single model for developmental evaluation were apparent. It became necessary to enhance the capabilities of the BSID or BSID-II with other tools. For example, these instruments tend to underestimate the word acquisition skills of young children. As an illustration, data reported by Smith (1926) from an early investigation of the pattern of word acquisition in young children is included in Table 4.

The Los Pasos developmental team has concluded from the data collected from the BSID-II, and from other testing instruments, that children with PADE are often insufficient in areas supportive

of language. As the Los Pasos children turned 18 months and beyond there has been a high incidence of slow expressive language development which is often accompanied by delays in receptive language abilities, deficits in phonological/articulation skills, and/or deficits in self regulation and socialization.

Refinements in the methods of assessing and intervening in the lives of infants and preschoolers are dependent on the use of multidimensional procedures. This involves combining medical, social, and educational service systems. Use of a multivariate assessment battery may be in line with Volpe's (1992) call for a more sensitive and specific method of identifying children with PADE or for identifying any child with developmental risk. Through early identification and utilization of existing well-researched programs, which facilitate language and learning development and meet caregivers at their level, early intervention may equip children to overcome the adverse effects of prenatal drug exposure and to better adjust to the stressful world they have been born into.

Table 4

Pattern of Word Acquisition by Ages of Children¹

AGE (Months)	NUMBER OF WORDS	GAINS
8	0	1
10	1	1
12	3	2
15	19	16
18	22	3
21	118	96
24	272	154
30	446	174
36	896	450

¹ Table 4 adapted from: M. E. Smith (1926). An investigation of the development of the sentence and the extent of vocabulary in children. University of Iowa Studies in Child Welfare, 3:54.

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Section Three:

Program Evaluation and Evaluation Outcomes

EVALUATION OF PROJECT LAGNIAPPE, CHILDREN'S HOSPITAL OF NEW ORLEANS

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Background

Maternal drug abuse and the human immunodeficiency virus (HIV) are two serious problems which threaten family structures and place children at risk for health and psychosocial problems. One of the most serious of these problems is the risk of abandonment. In 1991, a nation-wide study revealed that 1,149 HIV-positive children were living in foster care (Cohen & Nehring, 1994). The French Prospective Study of Infants Born to HIV-seropositive Women conducted from 1986 through 1993, calculated the child's cumulative risk of long-term or permanent separation from his or her mother was 37 percent at 60 months postnatal (Blanche, Mayaux, Verber, Landreau, Courpotin, Vilmer, et al, 1996).

One reason for abandonment of children born to HIV-infected mothers may be the absence of a father or other extended family members who could assume responsibility when maternal illness or death occurs. Results from a multi-state surveillance project demonstrated that 46 percent of HIV-infected mothers were the sole caretakers and only 30 percent of these mothers knew about child care assistance services (Schable, Diaz, Chu, Caldwell, Conti, Alston, et al, 1995). Another reason for abandonment is neglect and abuse due to maternal drug addiction. A study of all children in foster care in Oakland, California demonstrated that 78 percent of children came from homes where drug use was a primary reason for placement, and 94 percent of their mothers had a history of drug use (Halfon, Mendonca, & Berkowitz, 1995). The high rates of poverty among

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these women places them at risk for drug use, imprisonment, prostitution and other problems, which may in turn place their children at risk of abandonment (Bays, 1990).

In New Orleans, the prevalence of poverty, drug abuse, and HIV infection is high. By the end of 1995, 7,925 AIDS cases were reported in Louisiana. More than half of the adult and pediatric cases lived in the greater New Orleans area (Center for Disease Control, 1996). And the problem continues to grow. The percentage of women infected with HIV in New Orleans is steadily rising, and by the end of 1995, 18 percent of all AIDS cases were among women. Of those, 27 percent acquired the virus through injection drug use (Louisiana HIV/AIDS Annual Report, 1994).

Substance use among women in New Orleans is also prevalent. A study conducted at the Medical Center of Louisiana indicated that eight percent of the infants born in 1988 tested positive for cocaine (Louisiana HIV/AIDS Annual Report, 1994). In New Orleans, the City Health Department reported that in the first six months of 1991, 25 percent of the 2,815 persons admitted into public and private treatment facilities for drug abuse were women.

Poverty is another risk factor in New Orleans, particularly among children. Poverty statistics revealed that in 1990, 62,208 children under 18 years of age were living below poverty level in New Orleans (Children's Defense Fund, 1992). New Orleans ranks third among the poorest cities in America. Since all of the families in Project Lagniappe are impoverished, the effects of poverty on child caregiving and social support must be considered along with maternal substance use and HIV/AIDS.

Project Description

Project Lagniappe was funded in 1993 by the Department of Health and Human Services, through Children's Hospital in New Orleans, as a three-year demonstration project to prevent abandonment of infants and children due to maternal substance use or HIV-infection.

"Abandonment" had traditionally been defined as a caregiver leaving a newborn at the hospital.

However, this problem of “boarder babies” was limited in New Orleans, possibly due to the stability of extended families, even in impoverished families. It is important to point out that non-maternal care is not child abandonment, and may have a positive influence on child development if the placement is stable and enriching. In addition, services for families in crisis, such as programs to train foster families to care for HIV positive and substance exposed infants, had been established. However, as the AIDS epidemic began to take its toll in the city, along with increasing maternal substance use, a need for comprehensive, coordinated services for high risk families was recognized.

Project Lagniappe, which in Cajun French means “a little something extra,” was established to provide case management and support services to high risk families. The goal of the case management was to provide an individualized, comprehensive system of care which was culturally sensitive and promoted the health and autonomy of clients and their families. Support services, including mental health services, substance abuse counseling, respite services, and developmental interventions, were considered crucial in stabilizing families.

Methodology

In January 1996, Project Lagniappe contracted with a team from Louisiana State University and Tulane University School of Public Health and Tropical Medicine to provide a description of Project Lagniappe clients and to investigate the ways that the program affected their lives. Traditional impact evaluation was not possible because: (1) no pre-test measures were available; (2) high attrition and sporadic utilization of services by clients was common (resulting in non-systematic measurement of indicators); and (3) no comparable control group was available. The team, therefore, developed an approach that combined qualitative and quantitative methods to evaluate the project and describe the client population.

The evaluation consisted of five components: (1) a cross-sectional examination to describe demographic and clinical characteristics of the 59 active mothers; (2) a survey of case managers to determine their perceptions of the clients’ progress; (3) a standardized assessment to investigate clients’ perceived level of social support; (4) 19 ethnographic interviews of active

clients to explore issues of drug use, child care patterns, social support, and satisfaction with the project; and (5) an in-depth interview with the case managers to evaluate the progress of the project.

Results

Demographic Information

In the first three years of the project, 103 clients were enrolled. Of these, 62 were active during the study period. The 62 active clients included 59 biological mothers, one biological father, one maternal grandmother, and one maternal grandfather. Table 1 presents the demographic characteristics of the biological mothers. The majority of the women were African American (88 percent), with an average of three children. Mean maternal age was 32, and mothers had an average of 10 years of education. The majority of clients were HIV positive (69.5 percent). In addition to demographic variables, Table 1 presents information about maternal incarceration, homelessness, drug treatment history, child residence patterns, and involvement with Child Protective Services.

Table 1

Characteristics of the Biological Mothers (N=59)

Mean age	32 (range: 21-54)	Mean # children < 18 years of age	3
Race		Incarceration*	44.8%
African American	88%	Initiated drug treatment*	56.8%
White	10%	Homeless*	24.1%
Hispanic	2%	Investigation of child neglect/abuse by the State*	32.8%
Mean highest level of education	10th grade	% Children with other primary caregiver	43.0%
HIV status		* History of these events	
AIDS	13.5%		
HIV+	56.0%		
HIV-	30.5%		
CD4 (Among HIV+)			
< 200	27%		
200-500	50%		
> 500	23%		

Client's Perceived Social Support

Clients were administered the Children's Hospital Maternal Social Support Scale (CHMSSS) within three months of intake into the program. The survey measures client's perception of social support in the context of parenting. The self-administered measure included 22 items that respondents rated on a four-choice, Likert format from strongly agree to strongly disagree. Overall, clients' perception of social support was good as indicated by the degree of agreement with support statements (see Table 2). However clients rating of some statements indicated faulty support structures. These are highlighted in bold typeface.

Table 2

Women's Self-Perceived Social Support (N=40)

	% agree/strongly agree
Most people I know speak highly of me	85%
My family helps me without criticizing me or my abilities	70%
My friends help me without criticizing me or my abilities	83%
I like myself	98%
If I need a quick loan of \$10 there is someone who would let me borrow the money	85%
If I had to leave my home there is someone I could stay with a while	83%
If I need food there are people who could help me out	93%
There are several different people in my life with whom I enjoy spending time	78%
I don't get included in things with others	50%
When I feel lonely there are people I can talk to	83%
When I need ideas for how to deal with a serious personal problem there is someone I can turn to	80%
My family members are a major cause of stress in my life	40%
When I feel frustrated about day to day hassles there is no one to turn to for support	68%
I feel that I have nobody to turn to for emotional support during a personal crisis	63%
My faith (religion) is a source of support for me	88%

I feel there is someone who knows how to listen to and comfort me when I need it	85%
I know someone who will care for my children when I need help	90%
I have people outside my family who help me with my children	68%
I have family members who help me with children	80%
There is someone I feel comfortable going to for advice about problems I am having with my children	88%

Case Managers' Perceptions of Clients' Progress

A survey was conducted to evaluate the case managers' perceptions of their clients' progress. Case managers were asked to rate their active clients (i.e., mothers) on three indicators using a five-choice Likert scale. The following indicators were assessed: (1) effectiveness at accessing services for herself, such as medical care and/or substance abuse treatment; (2) effectiveness in accessing services for her children; and (3) commitment to the goals established by the client and her case manager. Case managers indicated that a little over half of the clients were successful in accessing services and were committed to achieving established goals. Table 3 presents these findings.

Table 3

Case Managers' Assessment of Clients' Status (N=51)

	% Agreeing/Strongly Agree
Effectively accesses medical care and substance abuse services	55%
Effectively accesses health care and other services for children	59%
Is committed to goals established	59%

Ethnographic Interviews

Ethnographic interviews were designed to: (1) describe how clients make decisions about health care and child care; (2) determine how substance use and/or HIV status affects these decisions; (3) determine how kinship and friendship systems affect these decisions; and (4) assess clients' satisfaction with Project Lagniappe. Using an interview guide, conversations were audio taped

(with client consent), transcribed, and then analyzed using Nu·dist software (Louisiana Department of Health and Hospitals, 1994).

A convenience sample of the active clients (N=62) were interviewed until consistent repetition of themes occurred. Nineteen clients were interviewed between March 1996 and June 1996. Client interviews were conducted in several environments: Kingsley House (where the project is housed), the HIV Outpatient Clinic, or in clients' homes. A \$10 food coupon was provided as incentive for participation in the study.

This subsample who participated in the study was comparable in demographic composition and HIV status to the total population of Lagniappe clients, as is indicated in Table 4. Eighteen women interviewed were African American, and one was Caucasian. The mean age of the interview participants was 33 years (range 24-54), and they had an average of three children under the age of 18 (range 1-7). Six of the women interviewed were HIV positive, four had AIDS and nine were HIV negative.

Table 4

Characteristics of Study Group Compared to Biological Mothers

	Active Clients (n=40)	Study Group (n=19)
Mean age	32 (21-54)	33 (24-54)
Race		
African American	88.0%	95.0%
White	10.0%	5.0%
Hispanic	2.0%	-
Mean highest level of education	10	11.5
HIV status		
AIDS	13.5%	21.0%
HIV+	56.0%	32.0%
HIV-	30.5%	47.0%
Mean number of children	3	3
Initiated drug treatment*	64.0%	73.0%
Incarceration*	43.0%	47%

Homeless*	23.0%	26.0%
Investigation of child neglect/abuse by the State*	35.0%	26.0%
% children with other primary caregiver	43.0%	41.0%

* History of these events

Drug Use Patterns

History of substance use was clearly indicated by the interview participants (n=17). Two of the 19 women interviewed had never used drugs and two denied drug usage, although there was indication of use in their records. Four of the 17 women who had a history of substance use, stated they had injected drugs. Although most women interviewed were polysubstance users, crack cocaine was used by all of the women who admitted to drug use or had mention of drug use in their records.

Most of the women interviewed indicated an early initiation (teenage years) to both alcohol and drug use. However, many women did not begin using crack until their mid-twenties or after they had at least one child. This initiation to crack may be associated with the historical introduction of crack to New Orleans.

Clients typically placed blame for their drug habits on persons other than themselves. The most common reason stated for initiation of crack use was pressure by significant others such as male partners or family members. One woman admitted the main reason she used drugs was fear of losing her husband. If she used, then he would "hang" with her rather than going out: "I went on drugs just to be with him." In another interview, a woman stated her nephew had turned her on to crack, and another woman said a friend she would hang with used, so she tried it [crack] too. Many stated their partners at the time were selling drugs.

Crisis was the most frequently cited stimulus for reinitiation of drug usage. These crises included: loss of employment, loss of partner (boyfriend, "man" or husband) by death or abandonment; depression; stressors related to the demands of multiple children; or general lack of coping skills.

Clients stated that life stressors were so great that drugs helped them escape and make their day easier. One women said, "I just wanted every day to be an easy day and using drugs made the day easier." Another woman stated that she started using after her first child: "I just couldn't take being a mom, and my mom was using drugs, so from watching her, I just started."

Several of the women in this sample (n=6) admitted to trading sex for drugs or money. Two who mentioned it during the interview associated it with their drug use, the other ran away from foster care at age ten and lived in the streets with "queens"; she began the sex trade at age thirteen.

Caregiving

The 19 women in this study had a total of 61 children. Sixteen of the mothers had at least one child currently residing with her. Twenty-five percent of the 61 children were living with someone other than their biological mother at the time of the interviews (See Table 5). Although most of the mothers interviewed were caring for at least one of their children, the primary caregiver for a significant number of Lagniappe children was someone other than the biological mother. Children in non-maternal caregiving arrangements were most frequently placed with maternal grandmothers, followed by the biological father, and the paternal grandmother.

Table 5

Child's Place of Residence

Primary Caregiver	Percent of Children (n=25)
Maternal Grandmother	9%
Biological Father	4%
Paternal Grandmother	4%
Adopted	3%
Sister	2%
Foster Care	2%
Aunt	1%

Heavy drug use, inpatient treatment, and incarceration were the most frequently given reasons for out of home child placement. One women stated, “you know when you want to party... I would make sure the baby went to my sister's.” This same woman also described an instance when she became intoxicated and forgot she had a baby: “I heard this thing crying and I thought ‘oh my God it's my baby’ and then I called my sister to come and get her.” One of the women stated that, during a drug-use binge, she was reported, by her sister, to Office of Community Services for child neglect.

Transfer of childcare was more frequent in HIV negative, substance-using women (60 percent) than HIV positive, substance-using women (40 percent). Therefore, it appears that non-maternal care is more strongly associated with maternal substance use than maternal HIV infection. Although a number of Lagniappe children were not living with their birth mothers, analysis of the interview data revealed that the majority of the children who were in out of home care were placed prior to enrollment in the program. Mothers, who were the primary caregivers of their children when they entered Project Lagniappe, tended to maintain their caregiving responsibilities while enrolled in the program.

Clients' Perceptions of Child and Health Care

Generally, the women interviewed had positive impressions of their childcare skills. All but one mother felt that they adequately met their children's health care needs and did not believe that their active substance abuse negatively affected their caregiving ability. Although the clients tended to state their child care abilities were good, many of the women indicated health problems with their children, including severe asthma and hyperactivity. One mother used substances during her pregnancy with one child, and avoided drug use during a subsequent pregnancy. In contrasting the two children, she reported that the substance-exposed child was difficult to calm, relative to the non-exposed child, and was hyperactive with an attention deficit.

In contrast to their reported ability to manage their childrens' healthcare, women interviewed indicated that their own health suffered as a result of drug use. Their report also differed from the

case manager's perception that the clients' effectiveness in accessing health care for their children was only average.

Support Systems

Data were collected on the clients' family composition, the current composition of their household, and the composition of their social support structures, including kinship and friendship networks.

The household composition of interview participants was diverse. In some cases, mothers resided only with their children, while other households included the mother, children, and other adults (including extended family members and partners). Two of the women were enrolled in residential treatment at the time of the interview, one of whom brought her two youngest children with her to the facility. Therefore, the settings of the households varied in addition to household composition.

During the interviews, the women were also asked to identify individuals who provided them with emotional and child care support. Some inconsistencies were found between the clients' responses to this question and their responses to the Maternal Social Support survey (CHMSSS). During client interviews, the women enrolled in Project Lagniappe generally reported that they had insufficient social support structures, whereas on the CHMSSS they indicated otherwise. Although many of the women come from large extended families, in the interview they identified few family members as reliable sources of support. Also, although family members were often designated as primary caregivers, clients seldom identified them as reliable sources of support. In some cases, children were placed with family members out of necessity rather than by maternal choice. One interviewee stated that her mother took her children into care in order to allow her to enroll in a three month treatment program. Later in this particular interview, the client indicated that she did not feel she could rely on her family for emotional support or child care. The reason for this apparent discrepancy is not clear.

Most HIV positive clients reported that disclosure of their status often resulted in emotional rejection from family members. A history of substance abuse also appeared to be associated with attenuated family relationships.

Although the interviewer did not directly inquire about clients' religious affiliation or spirituality, almost all of the women interviewed made references to church attendance or praying. It became clear that the church was an important source of support for clients. This was corroborated by clients' response to the standardized social support measure (CHMSSS). Several women indicated that they attended church regularly, whereas others stated that they read the Bible and prayed at home. Lack of attendance at church may have been related to HIV status or drug use. Only one of the women had disclosed to her church and pastor about her HIV status. None of the women had disclosed their substance use history. Interestingly, however, a number of women indicated that the Church, as well as their spiritual beliefs, played an important role in their rehabilitation.

Clients' Evaluation of Project Lagniappe

During the interviews, the women were asked to describe ways that the project had helped them, and to indicate program elements that they would like changed or added. Their responses fell into two main categories: logistics and counseling. Logistics is defined as coordination of client services, (e.g., medical referrals, drug treatment placements, financial support, food, supplies for children, and transportation). Overwhelmingly, the women cited social support as the main source of assistance received from case managers. Almost all of the women stated that they most valued the availability and receptivity of case managers. They especially appreciated that the case managers were willing to listen as well as advise. Moreover, the women interviewed reported that in addition to their assigned case manager, all other Lagniappe case managers were receptive to them. One woman stated, "it's more than just cab fare; we can talk to them and we don't have to care about what we feel, cause they'll understand..." Many of the women commented that Lagniappe staff were non-judgmental. One client related that "they accept you, even if you have a history of drug use or are 'loose.' They are non-discriminating."

According to this sample, the project has provided a structure and a teaching tool to help the women reorder their lives. One of the women who was in treatment at the time of the interviews stated, “they [the case managers] were a ‘role model’ in the sense that they demonstrated responsibility by having a job. And when they had a bad day, they learned how to get through it and didn’t use drugs. If I had a bad day, I turned to drugs. I wanted to have an easy day everyday. Also, the case managers demonstrated how to care and respect people and I watched them and learned from them.” Furthermore, many of the clients stated that Project Lagniappe offered “a positive place to go to talk with positive people about positive things, rather than being around negative people.”

The recurrent themes throughout the interviews on how to change the program focused on transportation, food, and child care. During this study period, the program lost its van service. Therefore many of the recommendations addressed the difficulties the women had in getting to clinic appointments or to group. Most of the women did not have childcare, so children had to accompany mothers to all appointments. It was necessary for many women to transfer buses two or three times to reach the center or clinic. Therefore, clients requested enhanced transportation assistance in Lagniappe. Presently, transportation is provided to clients in the form of bus tokens and taxi cab vouchers. However, according to clients, the van was more convenient and accessible than these other forms of assistance.

Other recommendations focused on parenting training. Lagniappe has been without a developmental specialist for over 18 months. Clients indicated that they missed this service and requested that the individual parenting interventions be reestablished. A few of the clients indicated that they were receptive to treatment but reported that adequate childcare was an obstacle to their enrollment. Four drug treatment centers in the city specialize in substance-abuse treatment for pregnant and parenting women. Mothers are allowed to enroll with up to two children under age 13. At least four Lagniappe clients have been admitted to these treatment centers. However, a limitation of these centers is that most clients have more than two children, or many have adolescent children, ineligible for enrollment. Therefore, for many women

interested in treatment, the problems of childcare remain an obstacle. There were also requests for enhanced childcare assistance, particularly designed for the children of HIV positive clients and for HIV positive children.

Additionally, gaps in community resources, (e.g., residential drug treatment options), were identified by clients. In general, however, the majority of the women were pleased with Lagniappe services and had very few criticisms. All were extremely happy with their case manager and the counseling and support they had to offer.

Case Manager's Perceptions: the Effects of Project Lagniappe on Clients

At the time of the interviews, three case managers were funded in Project Lagniappe. One of the case managers had been with Project Lagniappe since its inception; one began approximately two and one half years prior to the interview; and the other began six months prior to the interview. All of them reported that families enrolled in the program benefited in many ways from the services provided. In particular, case managers reported that they observed enhanced self sufficiency and self esteem in their clients. In addition, clients progressed in their established goals including extended periods of sobriety, employment, and in practicing harm reduction, according to case managers. It also appeared that maternal sobriety was positively associated with responsible family planning. Furthermore, case managers observed that parenting interventions provided in Lagniappe were effective in enhancing clients' parenting skills. They also reported that clients' understanding of HIV and other sexually transmitted diseases (including an awareness of prevention practices) increased as a result of health education interventions provided by the Pediatric AIDS Program and Project Lagniappe staff.

In assessing community resources, case managers commented that for women, more resources were available to assist with HIV-related needs than substance abuse. This paucity of resources for substance using women emphasized the importance of case management provided in Lagniappe. Without the program, it would be difficult for substance using women to identify and access needed services in the city. Drug users typically do not have the energy or organizational

skills to pursue treatment and other resources for themselves and their children. These difficulties are even more acute if the woman is a substance user and is mentally or physically unwell.

Discussion and Implications

Several themes emerged from the ethnographic interview process. First, multiple risk factors, (e.g., poverty, maternal drug use and HIV infection) are present in the families enrolled in Project Lagniappe. In turn, the stress encountered by these families is associated with maternal substance abuse and poor health. Moreover, possibly due to poor organizational skills and the compromised parenting abilities of addicted clients, many of the children in Lagniappe families are placed in non-maternal care. There is a cyclical nature to the way Lagniappe families function under stress. For example, crises trigger drug use and drug use triggers the transfer of child care to others. In addition, during times of drug use, clients report that they neglect their health, further limiting their functional capabilities.

The present research confirms that children in Lagniappe families are indeed at risk of being placed in non-maternal care, particularly when the biological mother is a substance user. However, the strength revealed is that maternal grandmothers are available to assume the role of primary caregiver, on either a temporary or permanent basis. The present study did not investigate the frequency of change of caregiving arrangements for Lagniappe children. However, stability of care is an important factor concerning the well-being of children.

The influence of poverty and cultural factors associated with non-maternal care is not clearly understood. It is possible that the practice of non-maternal care is the function of cultural or economic factors rather than maternal substance use or health status (Kilbride & Kilbride, 1994). Investigation of these factors was not the focus of the present investigation. However, in order to understand patterns of caregiving in the families served in Lagniappe and related programs, investigation of factors associated with non-maternal care is clearly warranted.

Conflicting evidence was obtained regarding the perceived social support of Lagniappe clients. Client responses to the standardized maternal social support survey (CHMSSS) indicate a positive perception of social support. Conversely, in the interviews, clients' responses indicate that many clients had insufficient support in their parental roles, even though extended family members frequently assumed caregiving responsibilities of their children. It is clear, however, that clients recognized their case managers as reliable, unconditional sources of support.

In summary, the results of the evaluation are favorable. Clients indicated that the project is extremely helpful to them with regards to their recovery, parenting, and obtaining health care. The evaluation also identified several areas of programming that could be enhanced to meet client needs. Future plans are to implement more child-focused care. Recently a Ph.D. level psychologist with ten years of experience has been hired to assume the developmental specialist position. Lagniappe has also contracted with several childcare agencies in the community to provide high-quality childcare to the children of HIV-infected mothers. Caregivers will be specially trained by PAP/Lagniappe staff to care for children affected by or infected with HIV. Respite care, provided by the personal care attendant on staff, continues to be available for Lagniappe clients, and case managers have been encouraged to more actively refer needy clients for this service. Furthermore, given that family members are often primary caregivers for the children, they may also be a target for intervention and support. Indicators (beside non-maternal placement) that may influence parenting and child development such as drug treatment compliance, imprisonment, homelessness, and reports to Office of Child Services, will be monitored on a monthly basis. This surveillance will allow for trend analysis and ultimately, an impact analysis will be feasible in the future.

This study demonstrates the utility of small-sample multi-disciplinary research. Through this process, a description of clients' perceived social support, perception of childcare, and health care management was provided, revealing a clearer picture of the psychosocial status of the clients. Furthermore, patterns of caregiving were established for the children served in Lagniappe. Therefore, the risks associated with maternal HIV and substance abuse were more clearly

identified. With this information in addition to clients' assessment of the program's strengths and weaknesses, plans for program development can be devised and implemented to most effectively meet client needs.

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Chapter 6

OPERATION PAR, INC. PAR VILLAGE : LONG TERM TREATMENT FOR WOMEN AND THEIR CHILDREN: PROCESS EVALUATION AND RESEARCH FINDINGS

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Historical Perspective

Operation PAR is a large comprehensive prevention, intervention, treatment, training, and research agency in Florida. The agency serves over 40,000 people annually in over 48 programs in Pinellas and surrounding counties. Since 1970, PAR has been a national leader in developing model programs for alcohol and substance abusers. Operation PAR has developed a service continuum for adolescents, adult males and women. These programs allow the agency to understand how addiction progresses from experimentation to chronic misuse of alcohol and other drugs. Over the past decade, PAR and other concerned agencies led the nation to focus attention on the increase of alcohol and substance abuse by pregnant, post-partum, and parenting women.

Early research findings on the effects of cocaine on the fetus, depicting prune belly syndrome and other serious physical abnormalities, were found to be unreplicable. These early studies predicted a future of “crack babies” overwhelming the schools and social service systems. Great attention and subsequent funding by federal agencies led to the first treatment that allowed women to bring their children with them to treatment.

Funders were particularly interested then and now in the treatment outcomes of those women. PAR found that when programs were specifically designed for women who were allowed to bring their children into treatment, they stayed longer and had increased positive outcomes.

Research evaluating the benefits to the clients' children, however, has not been well documented and remains an untapped source of important data. Operation PAR, despite inadequate funding for the children's evaluation, tested, evaluated, and documented the outcomes of interventions with these children. These important positive outcomes for the children of substance abusers cannot be overlooked as they provide great cost-benefit to society.

Despite documented positive outcomes, national and local interest in this issue has decreased. Over the past five years, PAR has noted great fluctuations in the numbers of substance abusing pregnant women referred to its continuum of services. The precedent setting *Jennifer Johnson v. State of Florida*, was one of the legal cases that first led to the prosecution of pregnant substance abusers. The subsequent extraordinary increase in early detection and referrals illustrated America's fear of "*crack babies*." Several mitigating factors led to a decrease in women referred for treatment early in their pregnancy. Eventually the Florida Supreme Court quashed Johnson's conviction. Other states had also refused to prosecute women under similar circumstances. Referrals of pregnant substance using women who were often fearful of unknown legal consequences decreased, especially those women in their first and second trimester of pregnancy.

Medicaid changes and the closing of the public health prenatal services led to private OB/GYNs seeing women they had not previously seen. These practitioners were often under educated about substance abuse and reluctant to become involved in what they considered a "social problem." This situation led to last trimester and post-partum referrals to drug treatment, precipitating an increased rate of smaller newborns, learning difficulties, and other developmental problems in the children. These mitigating factors led to a drop in early interventions and referrals of pregnant substance abusing women. The subsequent late pregnancy and post-partum referrals spiraled comorbid conditions of both mother and child. The future will continue to see increased numbers of women who use and abuse substances during pregnancy unless we refocus national attention to prevention, early intervention, and treatment.

The Development of PAR Village

Truly effective development of services is always a process and not an event. The experiential lessons learned over the years continue to be incorporated with valid research. PAR uses this data to build a continuum of services that will best meet the needs of specific populations. To understand the development of the model residential program PAR Village, it is important to look at the history of the agency's experience and knowledge gained by assisting substance abusing and addicted women.

PAR responded to several federal initiatives in the late 1980's. These efforts added to the body of knowledge about the environmental damage that results from the mother's drug or alcohol addiction. The term COSA (Children of Substance Abusers) now commonly used in the literature, originally came from PAR's first women's day treatment and children's developmental center. Through Operation PAR's vast experience in the area of treatment, it was found that early intervention services were needed for women's entire families including their children. The agency began to construct a continuum that began with prevention, intervention, and case-management. Services were further expanded in the coming years with the inclusion of outpatient, day treatment and residential treatment, and aftercare components. Some of these programs are noted for review.

The federally-funded program, Intervention Team ("I" TEAM), used a multi-disciplinary model which brought local social-service decision makers, providers, law enforcement, and medical services together as a team with the mission to correct systems currently in place that did not respond to women who needed services. The COSA program, the "I" TEAM interventionists, and the subsequently developed case management initiative, FACT TEAM, intervened with a vast majority of substance using women and their families in Pinellas County, Florida. The "I" TEAM examined the social support system and made successful changes which proved to be permanent, as opposed to other programs which provided temporary solutions causing havoc within the community when the funding ceased.

The Family and Children Together TEAM (FACT TEAM), a five-year initiative funded by the Abandoned Infants Assistance Act (AIA), reached out, not only to substance abusing pregnant and post-partum women, but also to those women who were “at risk” of abandoning, neglecting or losing custody of their children. This program was an attempt to intervene before a woman became involved in drug abuse and criminal behavior. It was PAR’s first women’s program that did not require a client to be involved in substance abuse. This assessment, case-management, and referral program collected data in different domains of the problem areas for the at-risk woman, allowing PAR to greatly improve services to families.

In 1986, the long-term residential treatment staff began to realize that the client’s children received little attention. Staff understood the multi-generational component of dysfunctional behavior, criminal thinking, and substance abuse. In addition, PAR began to see former clients’ children entering adolescent treatment. These juveniles had received no early intervention and consequently were likely to follow in their addicted parents footsteps. Without external financial support for children’s services, staff began a children’s outreach program by having children come to the center several times each week. The children visited their parents in the daytime, attended groups, activities, and prevention classes. They also participated in structured interactions with their parents. The adult clients were taught parenting skills to enhance their understanding of their children’s developmental growth and problems.

Years and years of working with generations of drug-involved families gave PAR the insight and knowledge required to intervene with the lives of children growing up in a world of dysfunction and drugs. This knowledge became the foundation of the current PAR Village program.

PAR Village has been a model program providing services to substance abusing women and their children since 1990. Following an initial National Institute of Drug Abuse (NIDA) initiative, the Center for Substance Abuse Treatment (CSAT) funded a five-year demonstration of gender-specific women and children’s services targeting pregnant, post-partum, and parenting women. Originally, NIDA funded a research project within PAR’s adult therapeutic community allowing

PAR to add a separate women and children's residential drug treatment program. The main purpose of this research effort was to determine the effects of allowing women to enter drug treatment with their children (e.g., their length of stay in treatment, completion rates, and follow-up outcomes). Women were randomly assigned into two treatment programs: one with their children and one without. Results showed that women who entered treatment with their children stayed longer, completed their treatment, and had more positive outcomes (especially in retaining or regaining custody of their children) than did their control group counterparts. As a result, PAR applied for continued funding through CSAT to allow PAR staff to continue their successful treatment models.

Past treatment efforts were solely based on white male drug and alcohol treatment strategies. Years of experience at PAR, found these traditional treatment paradigms ineffective with women, especially with women of color. Women tended to fare poorly in the traditional male-oriented treatment model; they had fewer days of treatment with fewer successes. Separating out treatment outcomes of women of color resulted in even worse results. It was apparent that the program needed to change and respond to the needs of women and their families. Gender and culturally specific services for women and their families have grown over the past years. Originally, this concept meant including separate women's groups in the traditional treatment model. Today, effective women's treatment is a full gender-specific continuum that includes prevention, intervention, case management, day treatment and long-term residential treatment, as well as services to children and other family members.

PAR's Therapeutic Village Developmental Center, built on prior learning with the COSA children's program, was developed to address the needs of children whose mothers participate in PAR's continuum of services. The children's program provides outreach and nursery school for children exposed to drugs either prenatally or environmentally. The children are assessed in the appropriate domains and educational developmental plans are developed. These ongoing plans and evaluations help staff, mother, and child to accomplish tasks and improve developmental delays seen in children exposed to drugs and alcohol. Today the PAR Village treats 27 women

who may bring up to two children with them, and 23 women whose children live in the community and may be part of the children's outreach COSA program.

Early Influences on Services for Substance Abusing Women and Their Children

Early research in the area of cocaine abusing women in the mid 1980's dismayed the nation with news reports of premature babies who cried incessantly and exhibited fine tremors. Cocaine, especially "Crack cocaine", was earning a reputation as a very damaging drug and one of the most addictive substances society had ever encountered. In addition, the prevalence rate of substance using pregnant women was increasing at an alarming rate. Hospitals were describing cocaine abstinence withdrawal syndrome seen in neonatal intensive care units as far more disturbing than even the withdrawal seen in heroin-addicted neonates. Chasnoff's (1988) early findings saw children who were profoundly affected with co-morbid factors of monumental proportions. Truncated limbs, prune-belly syndrome, small head circumferences, and low birth weight predicted future development problems of these children. The babies were difficult to console and appeared to have conditions, such as poor sucking and swallowing responses, which would further complicate their young lives (Chasnoff, 1988). Already overburdened school systems began to realize the detrimental impact of these drug-exposed children who would soon enter school in the next few years. Foster care systems, already at the breaking point, were inundated with children of substance abusers. By some counts, up to 75 percent of foster care situations were the result of substance-abuse affected families. To further alarm society, it was unknown how these children would behave as adolescents. Juvenile crime and drug use statistics were starting to climb.

Despite bringing much needed attention to a serious problem, these early speculations, although not entirely untrue, had many flaws. Chasnoff (1988) and others such as Janke (1990) and Kennard (1990) identified their subjects as "cocaine users" only. He suggested that the problems observed in both mother and child were a result of cocaine ingestion by the mother. Those critical of this early research included practitioners who knew from experience that current drug users,

especially cocaine addicts, seldom used only one drug. These cocaine users, unlike previous alcoholic or heroin addicts, tended to use anything available, especially when supplies of cocaine were limited. Professionals also knew that alcohol, cigarettes, marijuana, and even prescription drugs were used with cocaine. In addition, women who used cocaine, suffered from poor nutrition and were more likely to be exposed to sexually transmitted diseases including HIV. Attributing the effects on the neonate strictly to cocaine was misleading if not inaccurate. Findings were questioned primarily because they were extremely difficult to replicate. As a result, those responsible for public policy found the lack of substantial research evidence to suggest that perhaps cocaine was not as harmful as first believed. There appeared a movement following this early research that promoted a decrease in efforts to militantly intervene with pregnant substance abusers. The Village, however, continued to see children with developmental delays, especially in cognitive and verbal skills. Chasnoff and others would later acknowledge these flaws in subsequent research.

Operation PAR and other agencies who worked with pregnant substance abusers saw affected children at various ages. PAR, although never seeing the most difficult cases, did see children who had serious consequences of maternal substance abuse. Small birth weights, digestive and respiratory problems, and poor eating responses were not uncommon. Occasionally a Fetal Alcohol Syndrome child would be admitted, but usually the children's problems ran more to the middle ground. Occasionally children born to heavy drug users showed no immediate measurable effects, but showed greater difficulty later when language and other developmental delays became apparent. When the women's children, who lived in the community with relatives or foster care parents, came to the Village, PAR staff saw the effects of environmental substance abuse on children. Some of these children had also been exposed prenatally; all had been raised in homes where drug use was commonplace.

Professional staff saw developmental delays, as well as social and psychological problems in the majority of children who came to the Village. In 1995-96, 28 children at PAR Village were evaluated with the Hawaii Early Learning Profile (HELP). Based on these results, 11 children

(39.3 percent) displayed gross motor delays; 15 (53.6 percent) displayed fine motor delays; 16 (57.1 percent) displayed cognitive and language delays; 7 (25 percent) displayed self-help delays; and 9 (32.1 percent) displayed social delays. After careful planning and proper intervention, most children improved considerably.

Other problems in serving substance abusing women resulted from the method of determining whether a woman was using drugs during her pregnancy. Poorly trained professionals failed to recognize users. Some public health agencies relied on self-report which is often unreliable when dealing with users of illegal substances. Urinalysis can also be misleading. For example, although a positive urine screen shows the presence of drugs in the system, a negative urine test does not necessarily exclude drug use. It merely indicates that at the time of the screening particular drugs were not present in the system. PAR's years of experience have found that a thorough biopsychosocial assessment coupled with corroborating evidence is the best method of identifying substance abusers.

Although the social services approach to serving substance abusing women and their children had many problems, more troublesome were judiciary, legislative, and law enforcement attempts to address the incidence of drug use during pregnancy. A myriad of reactions occurred around the nation. Some states stepped up efforts to increase intervention and treatment by funding innovative demonstration programs to address women and children's programs. Other states rushed to pass laws that would make drug use during pregnancy a crime. Still other states tried to make their existing laws fit the problem (e.g., Florida).

Most states took the stance that in the sixty-to-ninety seconds following birth and prior to cutting the umbilical cord, the mother was "delivering illegal substances to a minor." This was already a crime in every state. Social service's stance was that seeking to prosecute and punish drug abusing women would result in an avoidance of prenatal care, an increase in abortion and increased use of the foster-care system. They further saw these efforts as pitting the fetus against

the mother, which they saw as counter to supporting families. The American Civil Liberties Union, Division of Reproductive Law took a strong opposing view to these laws.

On the other side, some believed that the mother was committing a crime against the unborn. They further felt that society, who would ultimately be burdened with costs of the woman's behavior, deserved their "pound of flesh". Also it was generally considered that a tougher stance on such behavior would deter women from using illegal drugs during pregnancy. Efforts were concentrated primarily on cocaine using women. It seemed the detrimental effects of alcohol, marijuana, and cigarettes to the developing fetus were largely ignored. The complications of arresting every woman who smoked during her pregnancy seemed insurmountable, consequently most attention focused on cocaine use during pregnancy. This would prove to be the undoing of their misdirected efforts.

Jennifer Clarice Johnson V. State of Florida - A Precedent Case

Jennifer Clarice Johnson had given birth to a son in 1987. She admitted she had used cocaine the night before the birth. In 1988, while pregnant with her daughter, she overdosed on crack cocaine. In January 1989, while in labor, Johnson told her obstetrician that she had used rock cocaine while in labor. The following day the Department of Health and Rehabilitative Services investigated allegations of abuse by Jennifer Johnson. Expert testimony established that if a mother used the night before delivery, the baby would be positive for benzoylecgonine, the metabolite produced when cocaine breaks down in the system. Subsequently, Johnson was originally convicted of two counts of delivering illegal substances to her children, referred to treatment, and appealed the decision in 1991 to the Fifth District Court of Appeal. The court of appeals overturned the conviction and the Florida Supreme Court upheld the Appellate Courts decision in 1992.

The court chose to support the belief that the state's best interest was served by making treatment programs available to pregnant addicts not in the prosecution of pregnant women. The threats of conviction and incarceration would only serve to drive women from prenatal care and services. This did not prevent law enforcement from arresting the women on other charges, if applicable.

There were many *Amicus briefs* written in support of this decision, including one from Operation PAR.

The rejections of legal sanctions, however, caused an unexpected negative reaction. The number of women who came to treatment early in their pregnancy fell. In fact, in the three months following the Supreme Court decision, no pregnant women were referred to any of PAR's programs. Post-partum women whose babies tested positive for drugs, however, came in substantial numbers. It seemed that since there was no emphasis on arrest and convictions, the police ceased to be involved, consequently early assessments were not stressed and fewer women came to treatment prior to giving birth.

PAR again made intensive efforts to educate the community about the benefits of early intervention. Referrals increased but never returned to the levels seen in the "*Jennifer Johnson Era*". As expected, women who presented for treatment late in their pregnancy had a higher incidence of obstetrical complications as well as more children born smaller with greater developmental delays.

Forcing people into treatment via the criminal justice system still proves to be controversial with diametrically opposed factions determined to have their way. Some professionals remain ambivalent. Certainly, it would not behoove a society to criminalize behavior during pregnancy, if for no other reason than the impossible nature of the task. Where would we stop? Should we prosecute women for eating poorly or smoking when we know these behaviors can have profound effects on the fetus? What about the father? Little research has been done on the genetic effects of the father's use of drugs prior to impregnation.

To further confound the situation, there is an erroneous belief that one must "hit bottom" before treatment interventions can commence. However, research and evaluation efforts continue to note that those who are forced into treatment do at least as well, and in some cases better, than their volunteer counterparts.

Medicaid Changes and HMO's

Another threat to the early detection of substance abusing pregnant women in Pinellas County occurred in the early 1990's when the urge to reform the welfare system began. HMOs began to offer alternatives to traditional Medicaid systems promising greater benefits and lower costs. At first they marketed their programs to Medicaid recipients who could choose to change to the HMO's. In the last two years, there has been a mandatory assignment to these managed care systems. There was a subsequent closing of the Health Department prenatal clinics and increased use of private OB/GYNs in the community. This presented the most crucial problem in regards to early intervention. Awareness and education concerning substance abusing women did not follow their healthcare. Private doctors knew little of substance abuse. Additionally, they were reluctant to approach their patients about the issues. The Health Department had long been partners with the community providers and had departments whose primary purpose was to identify drug-involved families and refer them to proper services. Despite the agency's efforts to educate and offer outreach to private doctors and clinics, awareness remains low as evidenced by low or nonexistent referrals from private doctors.

In an attempt to reacquaint the community with the problem, an anonymous urinalyses study was conducted in both the Public Health Department and the private OB/GYN offices (Chasnoff, Landress, & Barrett, 1990). The original hypothesis was that about one in ten pregnant women would be found positive for drug use. The Public Health Department's patients tended to be poor, minority, mostly African-American women. Private doctors' patients were more likely to be white and less indigent. The results shocked even the most experienced substance abuse professionals. It was not one in ten women found positive for drug use, but one in seven. There was no difference in the populations in their use of drugs, except white women used at slightly higher rates. Minority women tended to use cocaine more than whites; white women tended to use marijuana and alcohol more than African-American women. Despite these startling findings, private doctors still seem reluctant to test their pregnant patients for substances.

Drug treatment professionals are concerned that substance-involved women and their drug-exposed children will be overlooked as their problems continue to intensify. As PAR Village received women later in their pregnancies or post-partum, their newborns showed greater developmental problems as compared with women who came to the Village prior to their second trimester of pregnancy.

Research and Evaluation Findings

Research findings are so encouraging that to ignore the benefits of women and children's programs would be a great injustice. The original NIDA study conducted by Operation PAR and Dr. Patrick Hughes at University of South Florida, provided a randomized clinical trial to determine if retention in treatment and post treatment outcomes would be greater if women were allowed to bring their children to treatment with them (Coletti, Hughes, Landress, Neri, Sicilian, Williams, Urmann, & Anthony, 1992; Hughes, Coletti, Neri, Stahl, Urmann, Sicilian, Anthony, 1995). A battery of assessment instruments was conducted with the women at baseline, and at one, three, six, twelve, and eighteen months. Post-treatment evaluations were conducted at two, six, and twelve months after discharge. While in treatment, both control group and experimental group were provided with group and individual counseling, educational and vocational training, parenting and life skills training, medical services, substance abuse education, and relapse prevention. Fifty-three women were served by this experiment. Results were very supportive that positive outcomes increased when women came to treatment with their children. The experimental group had significantly longer lengths of stay. In fact, at six months, 65 percent of women with their children were still in treatment, as compared to only 18 percent of the control group. Post treatment custody saw the most startling result. Half of the women who came to treatment with their children retained or regained custody of their children at the six months post treatment follow-up, compared to none of the control group.

The long term evaluation project currently funded by the Center for Substance Abuse Treatment (CSAT) allows Operation PAR to continue to assess, treat, and follow women who come into

treatment with their children. Early findings continue to validate the hypothesis that women who bring their children, to treatment stay longer, graduate, and retain custody of their children, and improve in measures of psychopathology.

Although evaluation of the children was not originally funded, PAR continues to do baseline and interval testing. Originally the Village Developmental Center used instruments, such as the Denver II Developmental Screening Test (DENVER). This test tended to score development in gross measures. This caused several problems. For example, it did not catch subtle problems that would escalate in later preschool years. In addition, this instrument only measures substantial leaps in progress as opposed to smaller increments of improvements. Erroneous conclusions caused discouragement from both teacher and mother, who often saw their intense efforts score only slight improvements. In 1995, the DENVER was replaced with the Hawaii Early Learning Profile (HELP). This instrument allowed for much more subtle testing of developmental delays as well as recorded subtle progress. Teachers and parents could develop better Educational Development Plans and were much more encouraged with the progress.

Programs like PAR Village continue to learn and develop as they understand more about women substance abusers, their children and the nature of addiction. Unfortunately the future of such programs may be in jeopardy.

The Future

The Village is experiencing new challenges each year. The increase in MICA (mentally ill chemically addicted) clients has presented complex issues, such as, staff training needs, appropriate responsive program designs, and the high cost of medication interventions. In addition, most funding is based on providing services to substance abusers not mental health clients, who often require more attention, supervision, and lower staff to client ratios.

Post Traumatic Stress Disorders (PTSD) is seen in most of the children and their mothers. Years of chronic stress complicated by abuse, incest, poverty, and unstable living arrangements make women's brief time in treatment insufficient to address their complex problems. The most disturbing challenge to the staff of the Village is the increase in "sexualized" children. Many children are arriving at the Village so sexually traumatized that they have become perpetrators of abuse on younger children. Some very young children have witnessed or seen such distorted relationships that they attempt to have sex with their peers or talk in a very sexual way. These children are sometimes as young as three or four.

Multi-generational effects of substance abuse, criminality, poverty, and abuse are becoming more prominent in clients and children with extremely complex problems. These problems often require multiple referrals for community services that are either nonexistent or scarce. The push for managed care and reduced services puts additional stress on the problem. Substance abusers with chronic and severe addiction find successful treatment is not compatible with a few out-client sessions; rather, they often require long term efforts followed by extended aftercare.

In the future these issues will require more effort not less (i.e., greater funding not a reduction), if we are to truly see an improvement in the children of our nation. Research efforts must record not only the benefits to the woman but to her children who, if left unattended, may cost society hundreds of thousands of dollars in medical, foster care, treatment, school, and criminal justice costs. Specific positive interventions for both women and their children must be documented and implemented. Research evaluations have shown that women can and do benefit from gender specific services. Despite the budgetary struggle of federal, state, and local governments, we cannot reduce our efforts to intervene early in the cycle of drug abuse. To do so may save money in the present, but will increase cost exponentially in the future.

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Chapter 7

PROGRESS TOWARD PERMANENCY FOR HIV-AFFECTED AND SUBSTANCE-EXPOSED CHILDREN IN THE CHILD WELFARE SYSTEM: ILLINOIS' PROJECT "FIRST LOVE" COMMUNITY-BASED HOSPITAL AND FOSTER CARE PROGRAMS

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Introduction and Background

The Federal Abandoned Infants Assistance Act has helped make funding available for child welfare demonstration projects around the country for HIV-affected and substance-exposed children and families. In Illinois, Project "First Love" enables the state Department of Children and Family Services to provide programming at the community level. Through Chicago/Cook County's only public hospital, the Cook County Hospital Women and Children with HIV/AIDS Program (WCHP), case management, outreach, peer education, a buddy support program, mental health, and health education/chemical dependency counseling are provided for pregnant and post-partum women who are at risk for HIV infection, chemical dependency, STDs, or have a history of involvement with the child welfare system. Specialized foster care for HIV- and/or substance-exposed children is provided through the Ada S. McKinley Community Services McCares Program. Other services funded through "First Love" have included early intervention services, training on standby guardianship, and family/caregiver retreats.

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Most of the women with HIV in the project have a disproportionate number of burdens and tasks to negotiate for themselves and their children and, in general have experienced a high level of stress in their lives. For example, nearly two-thirds (62 percent) of a sample of 72 women served by the project have experienced domestic violence at some point in their lives, and a significant number have attempted suicide. Most, if not all, families need to deal with issues of grief and loss.

Many infected mothers lack sufficient social support, without others to rely on for help. Yet many have made remarkable progress toward keeping their families intact or regaining custody of their children. Some women have also begun to make plans for the future care of their children in the event they are no longer able to care for them or die.

The number of children and adolescents whose mothers have died of AIDS in Chicago is large and rapidly increasing. By the end of 1996, 1,600 will be motherless because of the disease. By the end of 2001 the cumulative number will reach 3,500 (Michaels & Levine, 1996). Increasingly, Chicago programs serving children and families with HIV are beginning to look at permanency planning issues for children who will be orphaned by the disease.

Originally designed to serve child welfare cases through community-based specialized foster care and hospital-based case management, support and prevention/education, Project "First Love" has begun to realize its own progress in achieving more permanency for children who are orphaned or who are in placement and cannot be returned home. This realization has come through anecdotal information and data collected by the programs that will be presented later in this chapter. In addressing the Project's progress, we acknowledge that there is little longitudinal or national research on what happens to children orphaned or left homeless by HIV and parental substance abuse, especially children in the child welfare system. However, a few recent studies are helpful. A report from the Pediatric Spectrum of Disease Project looking at HIV-exposed infants in six regions concluded that children born to mothers with

HIV who used drugs intravenously were more likely to be placed with an alternative caregiver than with the mother (Caldwell, Mascola, Smith, Thomas et al., 1992). A study of children in the French Prospective Study found that in France, while the majority of children who lose their mothers to AIDS are placed through child welfare, the role of the family as new caregiver increased gradually with the child's age at the time of the mother's death or inability to care for her children (Blanche, Mayaux, Verber, Landreau, et al, 1996). A study by the New York City Human Resources Administration Division of AIDS Services and The Orphan Project assessed children's living situations twelve months after a parent's death from AIDS. Fifty-eight percent of the children went to live with grandmothers or aunts; siblings remained together only 43 percent of the time; and the New York City Child Welfare Administration was involved in 14 percent of the cases. Forty-five percent had developed custody plans, but only 15 percent had utilized legal services to formalize their plans (Gamble, 1995).

Mothers' perspectives about their preferences and future planning activities are also helpful. In Project "First Love's" study of HIV-positive mothers at Cook County Hospital, 72 mothers were interviewed about their future plans for their children. Twenty-one indicated that they would like their own mothers to take the children; nine designated their sisters, and 22 designated other relatives. Twenty were not able to identify anyone, and only 14 had made legal arrangements for their chosen caregiver. Over time, we hope to document the permanency outcomes for the children of the women in the study.

Some programs around the country have also begun to focus on permanency planning, and their experiences can be helpful in charting further program development. One model of transitional foster care that promotes flexibility in meeting parents needs has been developed through the New York City Child Welfare Administration's Early Permanency Planning Program (EPP). EPP is designed for families in which parent(s) are HIV-positive and there is no family member or friend able to assume legal guardianship of the children. The program can prepare a foster home specifically for the children with either a relative or family friend,

or a foster parent identified while the parent is still able to care for the children. Through the program, families meet prospective foster parents and children spend time with the potential foster parents, which may include extended stays. The goal of the EPP is to ease the transition to foster care following the birth parent's death. Ultimately, it is expected that children in the program will be cared for by the identified foster parents after the parent's death, and may eventually be adopted by the foster parents (New York City Human Resources Administration, undated).

In 1993, Lutheran Social Services of Illinois (LSSI) developed the Second Family Program, a community-based program model focusing on permanency planning. The purpose of this program is to promote the stability and long term planning of families with an HIV-infected parent. Program goals are: (1) to increase access to information, referral, and counseling for HIV-infected parents wanting to plan permanently for their children; (2) to increase the number of HIV-affected children in permanent placements at or before their parents' death; and (3) to increase providers' awareness and knowledge of HIV-affected families' permanency planning needs and the subsequent program development issues. Families served in the program are not DCFS cases, but have a parent with HIV and want to begin permanency planning. Where placement with a relative is not possible, birth parents may choose from a pool of prospective parents recruited and trained for the program. Supportive services, including legal assistance, bereavement counseling, and support groups, are designed to assist with the transition.

Increasingly, public and community-based programs serving families affected by HIV in Chicago are looking at permanency planning processes and outcomes for their clients. The challenge for families in "First Love" also includes overcoming obstacles that led to involvement in the child welfare system. This chapter will describe the overall program design of the "First Love" project, report on program outcomes as they relate to permanency for the children and families, and summarize two psychosocial needs assessments of mothers in

"First Love". Finally, it will present some recommendations for future research and program development.

Overall Program Design, Case Examples, And Permanency Outcomes

The Illinois Department of Children and Family Services (DCFS) serves as lead agency for Project "First Love". DCFS offers child protective and child welfare services to children who are abused, neglected, and dependent; eligibility is determined following reports to a 24-hour hotline of harm to a child, of a parent's inability to care for a child, or a support services request. In 1994-95, 360,300 calls were made to DCFS for assistance involving 140,000 children reported for abuse and/or neglect. Forty-eight thousand children were placed by DCFS in substitute care under Department guardianship.

The population of substance-exposed and HIV-exposed children and families served by DCFS is large and growing. In 1994-95, 3,500 substance exposed infants were referred to DCFS; of these, 882 (25 percent) were taken into custody and placed by the Department. An additional 3,500 open family cases involving substance abuse were known to DCFS in 1994-95.

As of January, 1996, 436 HIV-exposed children were in DCFS custody. The Department had also identified 504 HIV-infected mothers in the DCFS system with a total 1,400 children. Of these mothers, 70 had died, leaving 167 affected and 52 infected children. At least 10 percent of these mothers have had multiple births of HIV-infected infants.

More than three-quarters of the substance-exposed and HIV-exposed children in DCFS care live in Chicago/Cook County. The Department estimates that the population of HIV-affected families that it serves increases by approximately 20 percent per year. It has designed the Project "First Love" components to provide, under contract, case management, supportive

counseling and mental health services, outreach, and specialized foster care to assist women and children who are HIV-positive and/or chemically dependent. By December 31, 1995, more than 4,000 women, children, and adolescents with HIV had received case management, peer education, health education, chemical dependency counseling, and buddy services at Cook County Hospital's Women and Children HIV (WCHP) Program. A total of 1,193 women and men, and 235 children had received case management services and medical care. Their families included at least 571 children affected by HIV. As of June, 1996, 130 intact families (with children at home and not in state custody) in the DCFS system were being served by Cook County Hospital's Women and Children HIV (WCHP) "First Love" Program. Twenty-two HIV- and/or substance-exposed children were placed by DCFS with the "First Love" McCares Program for specialized foster care.

In addition to establishing Project "First Love", the Department has worked to develop comprehensive policy and service plans for children in care who are HIV- and/or substance exposed. Department AIDS Project staff have taken a leadership role in providing direction to Project "First Love," and in designing program and policy enhancements to make the child welfare system more responsive to the needs of substance- and HIV-exposed children and families. The Department is also engaged in transforming the current highly centralized, fragmented statewide child welfare system into a child-centered, family-focused, community-based system which is integrated with local resources and is able to respond to the individualized needs of clients. The experience of Project "First Love" has shown that, through collaboration with community-based agencies, greater movement toward meeting permanency needs of children and families can be made for child welfare cases involving HIV and substance exposure. This progress can be documented through the achievements of the programs funded through the project.

Hospital-based Services: Cook County Hospital's Women and Children HIV Program

Program Design

Since 1989, Cook County Hospital's Women and Children HIV Program (WCHP) has provided services to women with HIV and their children. Among the program's unusual features are:

- All services offer a woman-centered approach. Prior to the program's inception, services in the AIDS community were designed primarily for men. In addition, care offered at WCHP is family-centered; that is, case management and supportive services are offered to the whole family, and not solely to the infected woman; and
- Comprehensive services, including case management, peer education, health education, chemical dependency counseling, and buddy services, are delivered at one site, preventing fragmentation.

Most of the women served by WCHP are at high risk for poor birth outcomes and/or poor parenting with their infants. "First Love" provides support through a health educator to conduct HIV education, counseling and testing with women who deliver babies at CCH, many of whom received prenatal care elsewhere, or in some cases, not at all. Women testing HIV-positive are immediately offered enrollment into a comprehensive clinic. Those testing HIV-positive and who are assessed with some vulnerability are targeted for outreach funded through "First Love". This includes home visits and "detective work" to find families that have been referred for services. This case finding work helps get vulnerable, mostly young HIV-positive mothers and infants into care.

Women referred to the Project "First Love" program of WCHP are either involved with the child welfare system or at risk of involvement. When women become clients in the "First Love" program, they are assigned to one of three full-time case managers funded through the

project. Case management with WCHP is designed to be holistic, and includes emergency housing and utility bill assistance, transportation support, facilitation of entitlement applications and appeals, access to legal assistance and permanency planning assistance, and child care during clinic hours. Women and children also have access to and receive primary health care and state-of-the-art HIV specialty care. Clients may also receive mental health services including family and individual therapy, chemical dependency counseling, and support groups and classes.

The program is augmented with components that help build client self esteem and confidence. "First Love" supports a parenting class and weekly early recovery group for HIV-positive women seeking sobriety. A buddy system maintains an informal parent-to-parent network of communication. Currently, WCHP is developing an intensive relapse prevention program designed for women in recovery who formerly had or presently have children in DCFS custody. Along with the parenting class and recovery group, the new intensive relapse prevention will incorporate DCFS materials that address nutrition, conflict resolution, self-esteem issues for parents and children, discipline methods, and child development.

The entire Women and Children HIV Program at CCH uses a culturally competent approach. Overall, the population served by WCHP is ethnically diverse. Patients serve on the program's advisory board, and patient satisfaction surveys are regularly conducted. Program staff are multiracial, and many are bilingual/bicultural English and Spanish communicators.

Case Examples

Two case examples illustrate the multiplicity of challenges and burdens faced by clients in the "First Love" Project at Cook County Hospital. The first example involves a mother with AIDS and her struggles realizing plans for her children. The second concerns a pregnant, HIV-positive teen.

Case Example #1

Geraldine is a 28-year-old African American woman with full blown AIDS and a ten-year history of cocaine abuse. She has dealt with the fact that she is dying of AIDS and has dedicated her remaining days to ensuring that her five children will be adequately taken care of in the event she should die soon.

Geraldine resides in a hospice unit of a suburban Chicago hospital. Three of her five children are DCFS involved: a girl aged 12 and two boys aged nine and seven. These three reside in relative foster care with Geraldine's sister. Geraldine's two youngest children (a girl aged five and a boy aged three) reside with their birth father, and have no DCFS involvement. All five of the children in the family have tested negative for HIV.

Geraldine has had a very difficult time relinquishing parenting of her children, and does not like admitting that she has become so vulnerable and helpless physically. She did, however, finally decide to entrust her children to her sister who Geraldine feels has some issues that need to be worked out in counseling. This, however, is a better alternative to placing the children in a non-relative foster home and possibly risking their being placed apart.

Originally, Geraldine had two other expectations as to where the children should go, but these proved to be unrealistic. Her partner, Roger, only wants to care for his two biological children and not her other three children. Her second option was her brother and his paramour, who only wanted the children by "default in the event that no one else would care for the children.

The biggest challenge for the WCHP "First Love" case manager was coordinating the various service agencies that were involved to one degree or another with Geraldine. These included an African American AIDS agency, DCFS, a hospice, a family program at the University of Illinois, and a drug treatment and interventions program. Many of the programs dealing with substance abuse had been primarily serving men up to the time of this project, and were based on a more male model of service delivery, with demands and expectations that are not realistic for women. Services offered through WCHP have included rehabilitative services, home nursing, counseling and art therapy for the children, prayer by the program chaplain, financial assistance with telephone and rent, and transportation to and from court and the hospital.

An illustration of Geraldine's tenacity and incredibly strong will despite her very progressed disease is as follows: When she came to Juvenile Court for a disposition hearing in October of 1995, she came in a rolling hospital bed with machines hooked up to her fragile body. She was accompanied by two paramedics, a nurse, and her "First Love" case manager. She had an impassioned fifteen-minute exchange with the judge, whom she informed that her children had not received assistance or services (bed vouchers, financial help) from DCFS. According to her case manager, "She told the judge she was going to stay around long enough to see her children taken care of, while all the courtroom spectators stood in awe." She was ultimately able to have her plans formalized legally.

Case Example #2

Sheila is an eighteen-year-old pregnant woman who had been a ward of the Illinois child welfare system for several years. Although she was referred by her DCFS worker, at eighteen she was no longer under the state's care because of her history as a chronic runaway. Sheila was not receiving prenatal care at the time that she came to CCH; she was also HIV-positive.

Sheila is very open and insightful. She disclosed to her case manager that she has known her HIV status since she was twelve. She feels her risk factor was heterosexual contact, which she attributes to her life experiences. She talked about her shame as a child due to her mother's alcoholism, about how she would walk the long way to school to avoid seeing her mother standing at the corner liquor store, and about the pain she felt when her childhood peers would tease her about her mother's behavior. She expressed the sadness she felt when her mother died a few years ago. She is estranged from her father, who now has a new family. Her thirty-four year old partner is the father of her expected child. He is without income, as is Sheila.

Sheila has been coming to WCHP for almost two months. She has not missed any of her numerous appointments. She attends the women's HIV support group each week, is enrolled in the WITS (Women and Infants Transmission Study) program, is receiving WIC and is applying for AFDC and SSI. She has enrolled in parenting classes. Her case manager is working with DCFS to reopen her case until Sheila and the unborn fetus are stabilized.

Permanency Outcomes

Family Support, Diversion from Child Welfare: One of the primary goals of DCFS in establishing Project "First Love" was to provide the support needed to prevent abandonment and divert children from the child welfare system. As of January, 1996 almost half (279) of the HIV-affected children served by Cook County Hospital's program component were involved with DCFS. Through its woman-centered approach, WCHP strives to engage birth mothers at the clinic and provide family-centered care to mothers and children in the same place. Important achievements of the WCHP "First Love" component as of January, 1996 included:

- More than 4,000 women with HIV and their families have received case management, peer education, health education, chemical dependency counseling, and buddy services.

- Many HIV-affected families involved with DCFS have been served by the Cook County Hospital component; 183 families have maintained intact (with no children in placement) as a result of the Project "First Love" interventions.
- Thirteen adults were DCFS wards as children, but all have maintained their own children at home and out of the child welfare system.
- Nineteen HIV-affected families served by Cook County Hospital's program have had their children returned to them from placement.

Program staff observations on program outcomes: Project staff report having had many clients that have courageously struggled to overcome abuse, addiction, and many other adversities. They are convinced that the DCFS Project "First Love" program demonstrates a serious approach to address some of the social conditions that contribute to poor parenting outcomes. They have learned that it is necessary to set up comprehensive care systems that bring together various service partners and clients in the decision-making process for effective policy making and procedures. WCHP's relationships with the DCFS AIDS project, several chemical dependency treatment centers, housing contacts, other health care providers, schools and client/parent leaders have been essential to conceptualize and implement a real family centered approach to women, youth and children at risk for, or living with HIV infection.

Further, "First Love" support simultaneously celebrates individual potential and actualization of success in overcoming poor odds. "First Love" philosophically and in practice helps meet its mission of serving its entire patient population with affirmation and respect. The program's optimism remains high, despite working with persons experiencing terminal illness, in part because staff have witnessed some real successes (McDonald, 1995).

Client Observations: Focus Groups of Chemically Dependent Women in Relapse

Prevention and Parenting Support Groups

The program's progress in helping families stabilize and function more productively is also confirmed by observations from clients involved in WCHP's intensive relapse prevention and parenting support groups for chemically dependent women. In June of 1996, members of these groups participated in focus groups concerning the importance of the support groups to them, the degree to which drug use interfered with their relationships with their children and their getting needed health care, and the factors that contribute to staying drug free or relapsing (LSC and Associates, 1996b).

Participants in both groups were very enthusiastic about the value of the support groups for them, and mentioned numerous ways that the group was helpful including sharing, being able to talk with others who were going through the same experiences, confidentiality, the ability to meet in a safe place where you can trust other members to ensure privacy, and the ability to have someone they could contact when they needed to (particularly when concerned about relapse).

With respect to relationships with children, participants generally indicated their drug use had had terrible effects on their relationships with their children, some going so far as to indicate that their drug use led a dissolution of their relationship with their children. Their recovery from chemical dependency, however, had led to re-establishing relationships with their children and knowing their children in ways that were not possible before. Parenting group respondents indicated that they were going to get counseling for their teenage children. They also indicated that they dealt more positively with their children and that the group lessened their frustration with their children. One group member described how it was important for her to share with others the difficulties she faced concerning her children:

To be able to come out and share...how you're dealing with your DCFS issues, as far as your children are concerned, and how to talk to your children about being positive, or for me, if I didn't have this group, it feels like I'm missing something. It's like I didn't go to church this week. You know, the spirituality of this group, the loving care, you know, the bond that we have...

Another woman spoke about re-establishing relationships with her children and grandchildren as a result of the support she receives in the relapse prevention group:

I spend more time at home, even though I never had to deal with DCFS, but my children, they really didn't know me, but now, I spend more time at home, and my grandchildren, they know me, very well, I spend a lot of time with them, and it makes my children jealous because I wasn't very much around with them and they say "You spend more time with them than you did with me."

Members of the parenting group talked about how their struggles with chemical dependency and the help from the support group had affected their relationship with their children:

Due to the group my children don't get cussed out any more.

The group gives me a balance, time to open up, I can deal with it right on, it's a safeguard, gives me a pretty positive way to deal with frustration, take time out.

I don't have my kids, so I'm trying to bond with them, not see them just as objects, this group teaches me they're human.

...my 13 year old, he asked why I didn't tell him. He was involved in some peer training on HIV. Materialistic things were taken care of [during chemical dependency] but not love.

It caused worry and fear, my being on the street, it played its part. I'm getting him counseling -- he's 15. I hear him express some feelings but he's happy I'm recovering. I'm working toward being an individual to recognize his needs.

Specialized Foster Care for HIV- and Substance-Exposed Infants: Ada S. McKinley Community Services Project "McCares" Program

Program Design

The McCares Program serves drug-affected and HIV-affected children referred by DCFS for specialized medical foster care. Most of the children are initially referred to DCFS' Emergency Reception Center by hospitals. Some are abandoned at the hospital, and some are taken into custody at the hospital because of drug exposure and their parents' inability to care for them. Before the McCares program was established, some of the children would have remained hospitalized or would have been institutionalized. Most of the children, including those who are HIV-exposed, have been exposed to drugs and are developmentally delayed. Ninety percent are African American and are also from families who live in poverty.

The McCares Program provides foster home recruitment, licensing, and supervision; intensive case management; in-home nursing; foster parent training; and respite care. The nurse consultant provides support to foster families and children through in-home training and medical support, up-to-date information on HIV in children and the care that children need; assistance in understanding and relating to medical service providers; skilled nursing, including at least monthly visits; in-home training for foster parents; and attendance at clinic appointments with the child and foster family to provide support and clarification as needed. Training sessions are conducted for prospective and licensed foster parents on such topics as HIV/AIDS, child development, medically complex children and their special needs.

Respite care is provided by nursing staff as needed. Many parents in the program do not have others available to them to provide respite care. The respite service provided through McCares has helped reduce foster family stress, and, because it is provided through a nursing service, has strengthened service delivery.

All children are referred to zero to three programs to ensure that their developmental needs are met. Case managers and the program nurse locate appropriate programs, work closely with staff assessing the child's developmental needs, and assist foster parents in resolving transportation and scheduling issues.

Case management in the McCares program includes weekly home visits during the first 90 days of placement, and linkage with community services. After 90 days, home visits are conducted twice monthly as the family becomes more versed in accessing needed resources and the child's care plan is established. Because many foster parents work outside of the home, McCares staff have located child care providers and worked with them through the interview and clearance process.

Regular case management interaction is maintained between DCFS and McCares staff. Working toward achieving permanency goals is an essential activity for all cases, with family reunification being the primary objective. When family reunification is not possible, the program works toward adoption or other long-term care possibilities for the children.

Case Example

The McCares specialized foster care program case example involves an infant exposed to HIV and drugs, referred to the program for specialized medical foster care.

M.G. was born on July 21, 1994. He was a premature baby, and had been exposed to drugs and HIV perinatally. Four of his older siblings were already wards of the Illinois child welfare department. M.G. was placed with the Project "First Love" specialized foster care "Mccares" program at Ada S. McKinley Community Services. Following his placement, further testing revealed that M.G. has Down's syndrome and also has seizures. He required an NG tube for feeding problems, had bronchospasms, alternating esotropia, and possible palsy.

Because of the specialized services available through Project "First Love" the foster care program was able to adopt an intervention and maintenance plan specific to M.G.:

- *First, his foster parents were assessed and counseled as to their own emotional stability and the capability to deal with the child's special needs. The foster family's daily routine also had to be adapted to adjust to M.G.'s special needs.*
- *Because staff in the McKinley foster care program have a relatively low ratio of staff to clients (8-12 cases per case manager), M.G.'s case manager was able to*

devote the amount of time needed in the home to help M.G. and the foster parents. The case manager was also able to advocate with other service providers to ensure that the family's needs are met.

- *The "First Love" foster care program nurse from Ada S. McKinley made weekly home visits and also attended clinical case staffings on M.G. She made sure that information and prescriptions from the medical staff were followed at home. She also trained and coached the primary caregiver on how to be alert and stay in tune with the child.*
- *Respite care was also provided to the foster family through the specialized foster care program. According to the foster parents, this additional service has helped prevent them from "burning out".*
- *Early intervention services have been provided to M.G. through an agency referral arranged by the foster care program. An individual family service plan was developed, with intervention focusing on M.G.'s speech.*
- *M.G. is being followed consistently by a local university hospital. He has experienced respiratory distress and pneumonia, but is currently doing better and started to thrive. He has begun eating solid food, and is alert and aware of his environment. His HIV status remains indeterminate.*

M.G. and his foster parents have developed a close relationship, and his foster parents are very proud of their accomplishments with him. Attempts to engage his birth parents in services and planning that might lead to his return home have been unsuccessful, largely due to the fact that his birth mother's whereabouts change frequently. Without the services provided to him through the specialized foster care "McCares" program and Project "First Love," M.G. might still be in a shelter program, or might have experienced several placements that may not have been able to provide needed support services to him and his foster family. The Illinois AIA program, Project "First Love," has provided critical case management, service coordination, and support for M.G. and his foster family that would not have been otherwise available.

Permanency Outcomes

According to the program administrator, provision of foster care appropriately supported through intensive case management, training, nursing and respite services has helped children in the McCares program make progress without requiring placement in more costly institutional settings. Most of the children in the program were developmentally delayed initially, but have shown marked improvement towards reaching developmental milestones. In-home intervention is making a real difference for these children, because it lends support to foster parents in their natural setting as they continue to work with the children. For the population of children who are

HIV-affected, specialized medical foster home care has also enabled the children to be cared for in a less restrictive and less costly setting by giving foster parents the know-how to manage the children at home.

Progress Toward Achieving Permanency Goals

In January 1996, nineteen children were enrolled in the McCares program. Of these, four children were moving towards returning home (three drug-exposed and one HIV-exposed child). For these cases, McCares monitors the progress of parents in fulfilling the requirements of the family's DCFS service plan by referring natural parents to needed services, providing them with tokens for transportation, securing documentation of compliance with case plan requirements, presenting progress reports to the court, and encouraging and facilitating visitation between the child and birth parents to maintain attachment. The agency also advocates for the birth parents, and provides information and clarification to birth parents concerning the court process and what the events in court mean for their family.

One child had been adopted, and seven others (six drug-exposed and one HIV-exposed) were moving toward adoption; some are in pre-adoptive placements currently. Adoption of these children is a less costly alternative for the State, since once the child is adopted, the cost of agency foster care supervision (approximately \$600/month/child) is no longer incurred. Also, payments to adoptive parents for "special needs" children are approximately 30 percent less than payments to foster parents for care. An additional seven children were in long-term foster care; it was expected that they would remain there until birth parents achieve their reunification goals or the children are freed for adoption.

It is significant that, as of January 1996, nearly two-thirds (63 percent) of the children in McCares were already progressing toward permanency in stable family environments. Although a control group of children not receiving specialized medical foster care services was not available for this project evaluation, it seems reasonable to project that many of these children would not have

made progress toward permanent living arrangements without the assistance provided by McCares for this population of children.

From the Foster Parents' Point of View

In June 1996, interviews were conducted with foster parents in the McCares Program. A qualitative evaluation was undertaken to examine the perspective of the foster parents on the McCares program, to examine their experiences in providing foster care, and to explore areas of health care and social service needs for these families (LSC and Associates, 1996a). In June, 13 foster parents were caring for 22 McCares children (but a total of 32 foster children were cared for by these families, including ten placed through other programs). All foster parents and foster children in the program are African American. Ninety-one percent of the children are drug-exposed, and 22 percent are HIV-positive or indeterminate. The children generally are hyperactive and have often experienced developmental delays and unusual illness.

Foster parents reported that they have good family support caring for these children, but little support from neighbors or friends. The support of the McCares Program is important to them. More than half rate their foster parenting experience as very positive, and foster parents rate their bonding as strong or very strong for 84 percent of their children.

Foster parents reported that 56 percent of birth mothers and half of the birth fathers are actively involved with their children. Over 60 percent indicate that at least one birth parent is seeking custody of a foster child. Sixty-four percent of foster parents have considered adoption, citing permanency for children, a good, safe home, and no longer having to obtain consents for medical care or to attend meetings as positive reasons to adopt. Negatives about adoption include the loss of financial subsidy through foster care payments, loss of services and support through the foster care agency, and loss of medical care, insurance and emotional support.

While some foster parents felt that it was important for foster children to develop a relationship with their birth parents, most foster parents were pessimistic about the real possibilities of family reunification. Their reasons included lack of consistent contact on the part of the birth parents, lack of a residence or income, failure of birth parents to meet visitation requirements, and continued drug use. A small number stated that the effects of HIV would adversely impact the birth parents' ability to care for their children.

Seventy percent of the foster parents in the McCares program indicated that their attitudes toward the birth parents had changed as a result of their participation in the McCares program so that they had developed an appreciation for the complexity of the birth parents' lives. Some had had virtually no contact with the birth parents and therefore had no reason for change. Several indicated they had had negative attitudes toward the parents, but had changed as they got to know them and better understand the parents' circumstances. Some seemed not to have changed positively about the birth parents, but rather had come to accept these parents as part of their foster children's lives.

On the whole, foster parents in this program seem invested in the long term future well-being of the children, and have participated in varying degrees in permanency planning.

Early Intervention, Family Retreat, and Standby Guardianship Training Services

Early Intervention Training

Project "First Love" hires a consultant to provide staff with early intervention training and support. Staff at both the WCHP and McCares Programs have been trained to:

- observe and understand infant development in the context of the caregiver-infant relationship,
- review current research and clinical effects of substance and HIV exposure on infant development, and

- observe and support strengths in parent-infant interaction in both intact and foster families.

The consultant also assists in developing new child welfare policy that supports better developmental outcomes in substance exposed infants.

Prior to the onset of Project "First Love" neither McCares nor WCHP program staff had training or experience in infant and early childhood development. Staff have learned to base much of their service planning on a child's development in the context of the caregiver relationship as well as substance exposure. At the McCares foster care program, staff and foster parents have developed skills in identifying strengths in the child's development as well as their relationship, with emphasis on understanding the effects of drugs exposure and ways in which to mediate its negative impact through comforting and helping regulate the infants through the caregiving relationship. This type of training has particularly allowed foster parents to feel more relaxed and confident in their role in supporting the development of the child and not to focus on the substance/HIV exposure.

At WCHP, the focus on strengths, rather than deficits, has helped staff to use the most positive intervention with birth parents. Even in the brief time clinic staff often see parents, they have reported that focusing on strengths in their relationship and the child's development has often made a marked difference in a parent's attitude about her child. Staff also feel they can offer parents information and support in a more meaningful way.

Family Retreats

"First Love" funded a Family Retreat in the fall of 1995. AIDS Pastoral Care Network, a local community-based organization, developed and coordinated a three-day retreat and a one day follow-up meeting for families and their children affected by HIV. Consortium staff and clients participated in the planning for the retreat. The retreat targeted caregiver families (foster,

adoptive, and relative caregivers of children who are HIV-positive) and birth families (including birth mothers, fathers, and children). Thirty-seven family members participated in the retreat, including 10 adults and 27 children aged one through sixteen. The retreat offered opportunities for entire families to participate in activities together and other opportunities for adults and children to engage in separate activities appropriate to their roles, ages, and development stages. Additionally, the retreat allowed for all to participate in reflective (discussions, support groups, learning experiences, meditation/spiritual reflection and group rituals) and recreational (crafts, indoor games, campfires and outdoor events) activities.

Standby Guardianship Training

Since Project "First Love"'s inception, Illinois became the fourth state to enact a standby guardianship statute, effective on January 1, 1994. Standby guardianship gives all Illinois parents the ability to petition the court for appointment of a standby guardian who can act when parents die or are unable to make and carry out day-to-day child care decisions. The new law also enables parents to appoint a short-term guardian to provide care and make important decisions for 60 days or less. Through Project "First Love", a series of trainings were offered to familiarize attorneys and social workers with the new law. Separate one-day trainings were developed and implemented for social workers and attorneys at three sites. In all, 429 professionals received the training, including 379 social workers and 50 attorneys.

"First Love" Families with HIV: Characteristics and Needs

Project "First Love" has sponsored research on the psychosocial needs of HIV-positive women with children in the Chicago area. A longitudinal study with two different points of assessment of a group of HIV-positive women with children has been conducted. The baseline assessment involved 72 mothers with HIV interviewed in 1993 (LSC and Associates, 1994) and the 1994 follow-up study included 50 of these women (LSC and Associates, 1995). Both studies were conducted by LSC and Associates with a team of researchers from the University of Chicago Department of Psychiatry. The studies used a semi-structured interview that was individually

administered to each of the women, examining their psychosocial experience approximately twelve months apart. Most of the women interviewed for the initial study and re-interviewed for the follow-up study were recruited from the Women and Children with HIV Project at the Cook County Hospital Primary Care Center; others were recruited from the Women and Infants Transmission Study (WITS) project at the University of Illinois Medical Center and the Family and Community Services Program at the University of Illinois School of Medical Social Work. The findings of this HIV Family Study and Follow up Family Study are summarized below.

General Characteristics of Participants

The women interviewed in the studies were largely living in the inner city, were poor, and were mostly unemployed. Seventy-four percent were African American. The majority in both studies had never married. Although a significant number had been married at least once, most of the women in the study were single. All were mothers, and most were raising their children as single mothers. Thirty-three percent of the women in the Time 1 study had one HIV-positive child; twenty-two percent in the Time 2 study had at least one child living with HIV infection.

Significant Life Events

At Time 2, the women reported a number of changes in their lives that had taken place since the first interview. For example, 48 percent reported changes in their primary relationship status since first interviewed. Sixty percent of the women had made changes in their living arrangements. Substantial numbers of women (up to fifty percent), reported experiencing a number of adverse or difficult events. Primarily these events included the loss of an important person in their lives (reported by 50 percent), typically due to HIV. Other events included experiencing major illness, divorce or separation from their partner, drug addiction, and diagnosis of AIDS. At Time 1, 39 percent of the women reported having been incarcerated at some time in their lives. Between T1 and T2, 16 percent were incarcerated for an average of 10 days.

Drug and Alcohol Involvement

Almost half of the women in the studies (48 percent at T1 and 46 percent at T2) reported current involvement in some type of drug or alcohol treatment program. At Time 2, ten percent were on a waiting list for drug rehabilitation. Substance abuse continued to play a role in many of the women's lives between Time 1 and Time 2, including drug relapses for some. Forty-nine percent reported drug use in the thirty days prior to their T2 interview.

Domestic Violence, Attempts at Suicide

In general, the women experience a high level of stress in their lives. Sixty-two percent of the women have experienced domestic violence at some point of their lives; 26 percent report such experiences in the last year. A significant number (56 percent) of women have attempted suicide at some point in their lives, and approximately a quarter of the women (23 percent) reported suicidal ideation during the last thirty days prior to their interviews. It is clear from their reports and other information gathered in the interviews that many of the women lack sufficient social support, and need not only peer support but also mental health services given the high level of stress in their lives.

Services and Needs

Most of the women have utilized a variety of medical and psychosocial services for themselves and their children during the last year. For example, 96 percent have used outpatient medical care, 86 percent have used case management, 80 percent have used transportation services, and 50 percent have used individual counseling services. Persistent difficulties remained at Time 2, including insufficient housing and transportation; for example, a third of the women reported needing housing.

Child Welfare Involvement

Forty-two percent of the women at Time 2 were involved (i.e., under investigation or having children in placement) with the Illinois child welfare system. The women's involvement was

typically related to abuse and neglect as a result of substance abuse. However, throughout the course of the study, 46 percent of the women had never been involved with child welfare. Some of the women in the study successfully ended their involvement with DCFS, but some also became newly involved with the child welfare system. Between Time 1 and Time 2, twelve percent of the women who had been involved with DCFS were able to resolve their situations and circumstances leading to DCFS involvement. At Time 2 these women were no longer involved with DCFS. However, eight percent of the women who were not involved with DCFS at Time 1 were found to have become involved with child welfare by the time they were interviewed.

Planning for Future Caregivers for Children

A large number of the women (72 percent) have made some type of plans for the care of their children should they become too ill to care for them. Most of these plans are informal arrangements. Only thirty percent of the women indicate that they have actually taken legal action to insure caretakers for their children upon their death. While many of the women have engaged in some planning for the future, a large number appear to need assistance with legal arrangements. Together, the studies indicate that these women living with HIV have a disproportionate number of burdens and tasks to negotiate for themselves and their children. Most of these women had not, as of their interview date, experienced severe illness due to their HIV. It is unclear as to the assistance and support they will have available to them as their health deteriorates. With the onset of health crises, more women may want to take legal action to ensure permanency for their children.

Some Recommendations for Research and Program Development

Research Recommendations

We described earlier in this chapter the need for further research concerning permanency planning for children and families affected by HIV/AIDS. It would be ideal if research would follow

families over long periods of time, from a parent's diagnosis to readiness for permanency planning to development of a plan to transitioning of children to new caregivers and, finally to aftercare. We do not know how well family members cope or function during many of these processes, and we do not know the long-term outcomes for the children or adolescents who are orphaned. Some research looking at some of these processes in addition to mental health needs has been initiated by the New York City Human Resources Administration's Division of AIDS Service, in conjunction with The Family Center.

However, research is needed which focuses on families in child welfare who may, with assistance, develop the capacity to make and carry out long-term private plans for their children thereby eliminating the need for state-supervised substitute care and public guardianship.

In Project "First Love", permanency planning has meant not only helping families plan for future care after a parent's death, but also keeping families together and functioning well. Other issues for further study have emerged through the Project "First Love" experience:

- Project staff are interested in learning more from women who have "gotten their children back" from foster care. Of particular interest are program and child welfare system characteristics that were user-friendly or made it difficult to achieve family reunification. Questions include: what role has visitation played in the family reunification process for families affected by HIV? How has improvement of life skills through participation in "First Love" programming helped families regain custody of their children? What role has prolonged sobriety played in gaining approval for visitation/regaining custody?
- Adolescents are a growing proportion of the population of mothers with HIV served in Project "First Love." Frequently, they are estranged from their nuclear families. Questions remain such as: how can outreach efforts be enhanced so that adolescents become engaged in supportive programming that can eventually provide them with

greater skills that will help them maintain sobriety, learn better parenting, and help them regain custody of their children?

- Some women involved in Project "First Love" have older children in DCFS placement, but have younger children with whom they seem to be doing well. It is important to ask about the factors that have helped contribute to this improved parenting ability.

Program Development Recommendations

Planning for the child's future should be an integral part of comprehensive services to families affected by HIV/AIDS. By helping the family to prepare for the mother's death and its impact on the child, it may be possible to promote care within the family rather than in a child welfare setting. But to do so, targeted and timely support alternatives must be in place. Specialized programming is needed to test models of assisting families with permanency planning. These models could include intensive social work and law approaches to helping families achieve readiness for planning and assist them in developing and implementing plans. They could also include mental health and emotional support programs for children, youth, and families, particularly therapeutic programs that are not available in private or public mental health facilities; in addition to voluntary placements for children whose parents are temporarily too ill to care for them, supportive transition programming for children and adolescents, assistance programs for private guardians, relatives, and other "new caregivers."

With the advent of new treatments that may extend the lives of persons with HIV/AIDS, more complex arrangements that lead to permanency for children may also be needed. Programs that can help better define the process of permanency planning for HIV-affected and substance exposed children and families in child welfare will be especially critical.

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Chapter 8

HELPING FAMILIES MAKE THE TRANSITION FROM HOSPITAL TO HOME CARE: EVALUATION OF A PROGRAM FOR FAMILIES OF TECHNOLOGY-DEPENDENT¹ CHILDREN

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Background

Recent medical advances have been accompanied by a rising number of children dependent for long periods of time on medical technology, such as ventilators and feeding tubes (Hochstadt & Yost, 1991). Most of these are children under two years old (Palfrey et al., 1990). For the majority of them, technology-dependence (TD) starts at birth, often because of extreme prematurity or congenital abnormalities. Drugs or alcohol exposure during utero do not in themselves cause chronic technology-dependence, but these substances may worsen other problems.

Experience with medical technologies has allowed these children to be discharged to home care. However, the care required is substantial and the literature about technology-dependent children and their families is sparse (Feinberg, 1992; American Psychological Association, 1992; Townes-Rosenwein & Rossky, 1995). Most research examines only intellectual or medical outcomes,

¹We use the term "technology-dependent children" to shorten the length of our title. These are children first.

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³A longer version of this chapter, which includes more detailed information on theoretical measurement issues related to attachment and on outcomes related to attachment, is available from the first author: 121 N. Easton Rd. Glenside, PA 19038

although social problems and family stress are predicted. Parents of these children face separations from their children during long hospitalizations, uncertain medical prognoses including whether their children will survive, and extremely demanding care once their children come home from the hospital. Because of the recency of the problem, once the children leave the hospital, few resources exist to help families care for their children (Office of Maternal and Child Health, 1995).

These factors put parents at risk for psychological or physical abandonment of their children with special needs who are known to be at increased risk for abuse or neglect (Hudson & Giardino, 1996). Attachment of parents to children is also likely to suffer. Thus, technology-dependent children are at risk to become “boarder babies”⁴. Because of their demanding care, these are the children likely to remain boarder babies longest. It is hardly surprising that children staying in the hospital past medical need who have handicaps and health problems other than substance abuse and HIV make up eight percent of the total “boarder baby” population (Child Welfare League, 1992).

The first part of this chapter discusses the backgrounds and characteristics of children who become chronically technology-dependent while in the Neonatal Intensive Care Unit (NICU). The second addresses the difficulties of measuring parents' attachment to children. Attachment is presumably an intervening variable which counteracts psychological or physical abandonment of these babies. The third presents the results of a program designed to alleviate these problems.

Program Description

The data in this chapter come from an AIA funded program located in a tertiary care hospital of a large urban center with a NICU and step down unit. The project involved interagency collaboration between three institutions: a community-based Early Intervention education

⁴We use the colloquial term “boarder baby” to refer to children who stay in the hospital past medical need, because this is a recognizable term for many readers.

program, an acute care hospital with a children's unit, and a children's rehabilitation hospital. The purpose of the project was to prevent emotional and physical abandonment of infants by supporting parents and encouraging attachment of parents to their child. All children in the NICU who became dependent on technology for 30 days or more were referred to the project. A clinical social worker provided services to families serving a maximum of five families at any given time. Services ideally began while the child was still in the hospital, but in some cases as soon as the child was discharged, and continued until the child had medically stabilized in the community. The latter was defined as three consecutive months in which there was no hospitalization or emergency room visit.

With each referral, the social worker immediately began intensive services, including home visits to the family while the child was still hospitalized and throughout the case as deemed helpful. The social worker followed the family throughout each hospitalization, even if the child was rehospitalized at another facility, until the point of medical stabilization in the community. This model allowed the family to have continuity with one trusted professional, service coordination, and system advocacy in the community. Thus, the services followed the family, rather than vice versa. An additional innovative aspect of the program was that the social worker coordinated both medical and social service case management, hoping to prevent unnecessary hospitalization and enhance the likelihood of keeping children with their families after hospitalization.

The clinical model for this program included family preservation (Meyers, 1991), developmental (Als, 1986; Hussey-Gardner, 1988), infant mental health (Fraiberg, 1980), and system coordination approaches. The model helped provide an integrated transition to care in the community delivered by a single individual the family had come to know and trust. Intensive and multifaceted services were provided to families (e.g., accompanying families to medical appointments, visiting the child and family in the hospital during rehospitalizations, giving concrete support and counselling). When the child returned to the community, the worker

monitored whether services in the community were meeting the family's needs, adjusted services as necessary, and coordinated resources.

Method and Collection of Background Data

Traditional social workers in the hospital filled out a Risk Assessment form developed by the project on every family whose infant met the criteria for chronic technology-dependence. The Risk Assessment form reflected factors creating risks for poor parenting and for emotional or physical abandonment of children with these medical problems. In addition to the health of the child, 29 family risk factors were identified. Risk assessment forms were completed on 208 families.

From these referrals, the social worker recruited families to be part of the program. After agreeing to participate in the project, families were randomly assigned to program and to comparison groups. Thirty-six (36) children and their families were followed in this randomized experimental design. Data were collected at three ecologically significant time periods: immediately after referral and while the child was in the hospital, just after returning home for the first time, and when the child was medically stable. Because many of the families were single parent households and fathers were not available, data from the family were collected from mothers or the child's major caregiver.

Data were collected by research personnel who were not blind to the group assignment of each family, because some information collected came from the social worker assigned to the case. In most cases, the data were collected in the families' homes. Direct observation of parent/child interaction during hospitalization was done at the infant's bedside. Background data on children and families at the time they were assigned to the program was obtained from medical records and semi-structured clinical interviews expanded and adapted from other researchers (Minde, 1980; Marcenko, 1990; Rohner, no date).

Background Characteristics of Children and Families

Data from the Risk Assessments showed the most prevalent risk was having a low socioeconomic status (38 percent), defined as below the poverty level or with less than a high school education. Other prevalent risks were having three or more children (19 percent), failing to telephone or visit the hospitalized newborn frequently (15 percent), having limited or absent prenatal care (14 percent), sustaining a previous emotional loss such as a death (12 percent), and having limited emotional supports (11 percent). Substance abuse was listed as a risk for nine percent of the children's mothers, while substance abuse for other members of the household was listed for four percent.

In addition to telephoning or visiting hospitalized infants infrequently, some families showed other signs indicative of potential psychological or emotional abandonment of their babies. Five percent expressed ambivalence about parenting (defined as having considered abortion, placing the child for adoption, or putting the child in foster care).

Degree of risk is also an important factor to be considered in this population. These data suggest a sizeable number of children with chronic technology-dependence are in family situations where the degree of risk is quite high. The vast majority of families had at least one family risk factor (68 percent). Only 25 percent had only one risk factor, and 12 percent had six or more risk factors. The developmental literature indicates that multiple risk factors increase the likelihood of poor developmental outcomes, and that the number of risk factors is more important than their content (Sameroff & Fiese, 1990). The degree of risk in particular families showed similar results; 15 percent of the cases where risk was present and degree of risk could be judged were found by social workers to present the highest risk of poor parenting (75-100 percent likelihood the risk factor would result in poor parenting). Only 23 percent of the cases where degree of risk could be assessed were judged to be in the least problematic category (zero to ten percent likelihood of poor parenting).

It is important to note that not only substance abusers or disadvantaged mothers were at risk of abandoning their infants and had inadequate contact with their newborns during the hospital period. Only 50 percent of the parents with inadequate contact or ambivalence towards parenting were substance abusers, and 38 percent of substance abusing households visited/telephoned infants frequently and were not ambivalent about being parents. Most substance abusing families were of low socioeconomic status. Families who had inadequate contact or were ambivalent about being parents were overrepresented among those with low socioeconomic status. Nonetheless, families who were not disadvantaged comprised 12 percent of the families without adequate contact with their infants or expressing ambivalence about parenting. Neither disadvantage nor substance abuse was present in the two “boarder baby” cases encountered in the program.

About half the families approached for the study declined to participate. Others were eliminated because of geographic location. The final randomized sample of the study was 36, half of whom were in each group. Risks in the final randomized sample, as identified by the Risk Assessment form, were similar to those for the referral population as a whole. A larger proportion of the randomized sample had low socioeconomic status (50 percent vs. 38 percent) and more had inadequate contact with their infants (22 percent vs. 15 percent) or were ambivalent about parenthood (12 percent vs. five percent). A greater percentage had suffered a previous loss (31 percent vs. 12 percent) and had limited emotional support (16 percent vs. 11 percent). Fewer had poor prenatal care, substance abusing families, and three or more children.

Data from the Risk Assessment forms were based on hospital social workers’ knowledge of the families at the time of referral. Once the families entered the program, the increased contact resulted in more information. Higher percentages of families were discovered to have substance abuse problems and histories of contact with Child Protective Services (CPS). These data indicate that traditional social work services in the NICU may underestimate the risks for poor parenting.

A typical client served in this program is a child with a gestational age of 23 to 28 weeks (67 percent) who has an extremely low birth weight. A parent of a typical client is African-American (89 percent), has an income below the poverty line, and has only a high school diploma (44 percent). About a quarter of mothers have less than a high school education (28 percent). However, clients of all socioeconomic levels and ethnic backgrounds are served by the program. The typical mother is in her twenties (61 percent); few are teenagers (11 percent). She is single and lives with relatives (44 percent) or with her sexual partner (39 percent). Only a small proportion of the infants are known to have been exposed to drugs or alcohol or to the HIV virus in utero (11 percent).

Except for apnea monitors, children generally no longer used medical technology when they first went home, which was typically at two to four months old (61 percent). Almost all children went home from the hospital with their parents, although relative care was a necessary support in some cases. Most children were rehospitalized at least once before becoming medically stabilized in the community (56 percent). The average length of service in the program was eight months.

Issues in Measuring Attachment of Parents to Infants

Selection of measurement tools to assess the attachment of parents to their infants was hampered by several factors. First, there are no accepted tools to measure this important construct. Second, the definition of attachment itself is unclear. Third, neonates and young infants with chronic technology-dependence lack the typical responses to their parents of less medically complicated children. Consequently, these infants may not reinforce their parents as well as average infants, and the behaviors of parents that indicate attachment to their children may be different than in more average pairs.

There have been very limited attempts to define and measure attachment of children (over toddlerhood) to adults (Main, Kaplan, & Cassidy, 1985) and of parents to infants or toddlers (Bretherton, Biringen, Ridgeway, Maslin, & Sherman, 1989; Kirkland, 1996). Neither Bretherton

et al.'s or Kirkland's approach is currently adaptable for parents of young infants who are chronically technology-dependent.

In addition, there is disagreement about the difference between attachment, bonding, and parenting. The psychological research literature distinguishes between attachment and bonding. Bonding is defined as occurring between a parent and child at the beginning of their relationship before true attachment is present (Klaus & Kennell, 1982). It is often compared to the reflexive relationships between young animals and their parents. Clinical literature often uses these terms interchangeably. However, in clinical work it seems sensible to separate these constructs. In the present case, we are concerned with parental feelings which are strong enough to withstand long periods of separation, the possibility of loss through death, atypical responsiveness on the part of the infant, and extraordinary caretaking demands. A genuine attachment cannot exist right after a newborn's birth, even if strong parental bonding occurs, since the pair do not know each other well. Also the relationship has yet to be tested for its ability to withstand considerable stress, as relationships characterized by "secure attachment" can (Waters & Deane, 1982). In this chapter, this problem was approached by examining the construct validity literature on attachment and determining core aspects of attachment which persist across the lifespan. These core aspects were applied to the problems of parents with infants who are technology-dependent, and then measurements of these aspects were selected.⁵

The construct validity literature on attachment often questions whether attachment is a construct (Rushton, Brainerd, & Pressley, 1983; Waters & Deane, 1985; Masters & Wellman, 1974; Waters & Deane, 1982; Thompson, Lamb, & Estes, 1982; Sroufe, Fox, & Pancahe, 1983; Cohen, 1974; Weinraub, Brooks, & Lewis, 1977). Authors who consider it a construct are likely to define attachment more broadly, not as specific behaviors such as crying when someone leaves or smiling when they return, but as an organized coherence of behaviors in relationship to each other (Waters & Deane, 1982). This broader definition allows for the changing expression of the same

⁵ Our approach to this issue is heuristic; the dimensions are likely to overlap and additional factors could be added.

concept at different developmental levels. Adults show they are attached differently than babies. Ainsworth's definition of attachment fortunately transcends age and, therefore, can be used as a basis for adults' attachment and selection of measurements. Ainsworth has listed six criteria critical to attachment formation (Ainsworth, 1973; Cohen, 1974)⁶ (see Figure 1).

Figure 1
Aspects of Attachment from Ainsworth

- Specificity>Selectivity
- Duration
- Reflects Maturity Level
- Affective Implications
- Proximity/Maintenance Behaviors
- Learning

In addition, we have adopted a transactional model (Sameroff & Chandler, 1975) of attachment. This model views the relationship as bidirectional, (i.e., parent affects baby and vice versa), and the context affects both. An interaction of a large number of variables occurs to promote or detract from attachments. Barriers/enhancers of attachment may include such variables as parental mood, parental stress, social support, history of parent, opportunity for acquaintance (e.g., distance from the hospital), internal working model (differentiation from own parent, from infant), infant characteristics, and skill in caretaking. The parent's sensitivity to the infant's cues is probably both an enhancer of attachment and an indication of attachment (Weinraub, 1991). When the parent is sensitive to the infant's cues, the infant responds to the parent in more reinforcing ways. This sort of interchange causes the parent to become increasingly attached.

⁶More recently, Ainsworth (1989, 1991) has added another criterion to her definition of attachment, seeking to obtain security and comfort by means of the relationship to the other person. She, therefore, believes the relationship of a mother to her child is an "affectional bond", and differs from attachment, because it lacks the security seeking component. Bowlby (1988) makes a similar distinction between attachment and parenting. Bretherton (1987) sometimes makes this distinction, at other times refers to the "parental attachment" system.

It is important to distinguish among skill level in caretaking, parents' sensitivity to the cues of their infants, and attachment. These three concepts are often confused. Nurses in the hospital can be very skillful with young infants and sensitive to their cues, but are not necessarily attached. Mothers whose skill levels are lower may be more attached. Being responsive to a child's cues is not the same thing as having concrete skills in areas like feeding or medical care. A parent can know a child needs something, and in that way be responsive, but not know how to deliver it competently. Skill areas themselves can be quite specific. Children who are premature and/or have special medical needs may require particularly unique caretaking skills when they are in physical distress. We measured the following barrier/enhancers and aspects of attachment (see Table 1).

Table 1
Areas Related to Parent to Child Attachment Assessed

AINSWORTH ASPECTS OF ATTACHMENT	AREA	BARRIERS/ENHANCERS	MEASUREMENT(S)
Affective implications, Duration	Drive to connect	Unknown	Maternal Separation Anxiety Scale, Strength of feelings despite separation, affective sharing in parent/child interaction
Specificity/selectivity	Selectivity (specialness)	Unknown	O'Donnell paragraph on own child vs. on other child
Learning, Proximity/Maintenance Behaviors	Sensitivity to cues	Skill, Opportunity for acquaintance	NCAST, Parent/Child observation, Visits and calls, Interview
Duration	Capacity to form attachments	Internal working model, History of parent	O'Donnell paragraph about child, Interview
	Other	-Social Support -History of infant -Socioeconomic and cultural background -Interfering affects (parental mood) -Ability to tolerate stress (parental stress)	-Interview -Medical Chart -Interview -Beck Depression Inventory, IPAT Self Analysis-Parenting Stress Index

Measurement Tools

The following measurement tools were selected. Family phone calls and visits to the hospital, and families' attainment of social work goals were assessed continuously. The remaining data elements were collected at specific points in time (see Table 2).

Table 2
Schedule of Data Collection

INSTRUMENT	IN HOSPITAL	JUST HOME	AFTER STABILIZATION
Social Work Interview	X		X
Maternal View of the Child	X	X	X
Parenting Stress Index	X	X	X
Maternal Separation Anxiety Scale	X	X	X
Beck Depression Inventory	X	X	X
IPAT Self Analysis	X	X	X
Parent/Child Interaction	X	X	X
Bayley I			X
Satisfaction			X

The initial Social Work Interview is described above. The final semi-structured clinical interview was similar and reflected facts about the family at the time of the child's medical stabilization.

The Maternal View of Child (O'Donnell, 1984; O'Donnell & Vaugh, 1985) is a projective device measuring the parent's differentiation from her child, the ability to see the child as separate and autonomous. Scores indicate a parent's capacity to form attachments, and also reflect the parent's internal working model about the child. The parent wrote a paragraph describing his/her child and a second one about a child in the hospital the parent knew best that was not his/her own.

Comparing the two paragraphs provided a measure of the unique feelings parents had about their own children compared to children with similar problems.

The PSI, or Parenting Stress Index (Abidin, 1990), assessed the parent's perception of stress about parenting the identified child. Stress is assessed in two areas: emanating from the child's characteristics and from the parent's personality/situation. Specific parental affects were measured by three scales. The MSAS, or Maternal Separation Anxiety Scale (Hock, McBride, & Gnezda, 1989), assessed the amount of anxiety the mother felt about separation from her child. The BDI, or Beck Depression Inventory (Beck, 1972), assessed the caregiver's depression, and the IPAT Self Analysis Form (Krug, Scheier, & Cattell, 1976) his/her general anxiety.

Parent/child interaction was measured by the NCAST Teaching Scale (Barnard, 1980) after medical stabilization, and also just after the child came home if the child was mature and healthy enough to be appropriate for this scale. For children in the NICU and those at home unable to use the NCAST, we developed our own parent/child interaction tool.⁷ This tool adapted some items from the HOME version for disabled children (Caldwell & Bradley, 1984) and rated several aspects of parent behavior thought to be important in interaction and to be indicative of attachment: involvement, skill, sensitivity to cues, affective sharing, affective tone, proximity seeking. Parent/child interaction was rated in the context of the child's medical condition and the instructions medical staff had given to parents. This approach is consistent with our overall contextual and transactional model.

Bayley Mental and Motor tests (Bayley, 1969) were given to each infant at the time of medical stabilization. These tests measure developmental functioning. Finally, the caregiver completed a satisfaction survey. This survey not only measured overall satisfaction, but asked whether the caregiver had used various parts of the program, and if so, whether these had facilitated the caregiver feeling closer to her baby.

⁷A copy of the instrument along with interrater reliability information can be obtained from the author.

Results and Outcomes

Initial assessments were interesting in several ways. Mothers' interactions at the bedside showed the poorest ratings in affective sharing with their child or about their child. If affective sharing is related to the "drive to connect," these data suggest some tentativeness on the part of the parents. Mothers initially were learning to read the cues of their children with special needs. In the beginning, mothers were not as good at sensitivity to nondistress cues or skill in responding to cues as they were in other areas, such as medical or child care skill/cues. Nonetheless, mothers' initial involvement at the bedside was relatively high and their affective tone with their babies generally quite good.

Most of the mothers (67 percent) had had a good relationship with their own mothers, 21 percent had had a poor one. About half had had a good relationship with their own fathers, and 30 percent had had a poor one. However, only 40 percent had a good relationship with their partner, and 34 percent had a poor or mildly negative relationship. About a quarter had very little to no support from their partners; 11 percent had no support from other people besides their partners. These incoming characteristics, particularly the relationship of the mothers to their own mothers, form a context for learning attachment relationships. These early relationships, therefore, are likely to affect the mothers' capacity to form secure attachments with their own children and their likelihood of visiting their children in the hospital, as Minde et al. (1980) have shown with mothers of premature infants.

It is often thought that contact between parents and baby immediately after delivery enhances the bond between parent and child (Klaus & Kennell, 1982). When medical problems exist, it may be impossible for parents to have early contact. Indeed, less than 40 percent of the mothers saw, touched, or heard their babies right after birth. A few more fathers than mothers had early contact with their babies. However, 36 percent of fathers' relationships with the mothers had worsened since the birth of the child, and only nine percent had improved. About a quarter of the fathers

had minimal involvement with the new baby, and only about half (46 percent) had a lot of involvement. On the other hand, 26 percent mothers had better relationships with their own families since the child's birth, and only three percent had worse relationships.

Unfortunately, randomization did not eliminate the initial differences between the groups. The comparison group turned out to be a more advantaged group. The mean birth weight for the program group was 1,038 grams, for the comparison group it was 1,476 grams ($p < .075^8$, 2-tailed Mann-Whitney). Household income was also greater in the comparison group. The mean income per year was \$13,695 in the program group and \$29,863 in the comparison group ($p < .05$, 2-tailed Mann-Whitney). Similarly, an initial rating of the quality of mothering (from the Social Work Interview) showed the comparison group to be superior to the program group ($p < .075$, 2-tailed Mann-Whitney). Ratings of parent/child interaction at the bedside in the hospital and history of previous involvement with CPS also show similar differences between the groups. These initial differences affect the interpretation of the results.

Outcomes

Attrition of nine families occurred by the end of the study. Half of the attrition occurred in the program group. These nine families included the four who were referred to CPS. Three of these CPS referrals came from the program group. These data show that some families were unable to benefit sufficiently from the program to prevent significant risks to their child. Nonetheless, several short-term outcomes are already apparent for the families who did complete the program. Initially, parental mood and stress were barriers to attachment; thus, 31 percent of parents were depressed, 19 percent mildly/moderately and 12 percent severely; 12 percent had significantly elevated anxiety. Most (88 percent) were more anxious about separation from their babies than the average parent, and 69 percent were significantly more anxious. A typical client was experiencing more than the average parenting stress (69 percent), with 12 percent experiencing significantly elevated levels of stress.

⁸The sample was so small, we elected to report p's of .10 and under to increase our power. All statistics were nonparametric and used the Exact Test method of calculation.

The level of anxiety, anxiety about separation, and depression dropped during the program for the program group ($p<.05$, 1-tailed Wilcoxon for MSAS; $p<.01$, 1-tailed Wilcoxon for IPAT; $p<.10$, 1-tailed Wilcoxon for depression). There was no significant drop in depression or anxiety in the comparison group; although anxiety about separation did drop in the comparison group ($p<.10$, 1-tailed Wilcoxon). None of these results can be explained by regression to the mean. The small sample sizes make it even more surprising that significant results occurred (N=13 program group, N=14 comparison group).

Mothers in the program group also learned to become more sensitive to their infants cues. Several indicators show that mothers in the program group were able to understand their infants developmental problems better after intervention. Initially, there was no difference between the groups in knowledge about premature babies and children with technology dependence; sixty percent had no knowledge about these topics before the child was born. The comparison group initially was a little better informed. Examination of only those individuals with some knowledge about these topics also yielded no difference between the groups in the degree of problems they expected their infants to have later on; most expected some children to do well. Likewise, the groups initially were similar in the amount of information they sought about these issues; 67 percent were actively seeking such information.

By the time of medical stabilization in the community, 88 percent of the program group versus 57 percent of the comparison group understood that premature babies' development should be viewed in terms of corrected age ($p<.075$, 1-tailed Mann-Whitney). This was true despite the fact that most babies in both groups were premature. At the point of medical stabilization, the program group was also more likely to be actively seeking information about babies who are premature or technology dependent (65 percent versus 29 percent; $p<.075$, 1-tailed Mann-Whitney). The comparison group actually did more seeking of such information initially than by the end of the study ($p<.05$, 2-tailed Wilcoxon), whereas there was no change for the program group. Knowledge about prematurity and technology dependence did increase over the course of

the study ($p<.001$, 2-tailed Wilcoxon, N=27) across the entire sample. Again, however, the effect was stronger for the program than the comparison group ($p<.01$, 2-tailed Wilcoxon for program group, N=16; $p<.10$, 2-tailed Wilcoxon for comparison group, N=11), although the larger number of data points in the program group might have accounted for this latter difference.

It was somewhat difficult to interpret the results on parental stress because the comparison group was initially a great deal more stressed than the program group. The comparison group was also more variable in perception of parenting stress than the program group, another indication that randomization did not achieve initial similarity between the groups. Mean data indicate that parents thought more stress was coming from the child than from coming from their own situation. This latter result is expected for children with special needs. At the point of medical stabilization, parents in the program group were feeling less overall parenting stress ($p<.05$, 1-tailed Mann-Whitney), less stress from depression, and less restriction from parental role than the comparison group ($p<.10$ and .075, 1-tailed Mann-Whitney, respectively). These results may reflect the fact that the comparison group was initially more stressed in these areas. Other final differences between the groups reflected incoming differences. The program group felt less stressed from the child's characteristics by the end of the study than before ($p<.10$, 1-tailed Wilcoxon). In the program group, as well, mothers' health improved between the time the child came home and the end of the study ($p<.10$, 1-tailed Wilcoxon). Statistically significant improvement also occurred in the comparison group, but this group started with very high levels of stress so regression to the mean may explain the results. Stress about parental attachment to the child did not differentiate between the groups nor show meaningful results.

Mothers as a whole felt more parental stress because of social isolation at the end of the study than when the child first came home ($p<.05$, 2-tailed Wilcoxon). This result indicates that some forms of stress increase with time; and, therefore, continuing monitoring and help for families may be necessary beyond the point of medical stability.

Another interesting result was the effect on fathers' employment, a potential barrier/enhancer of attachment. At the end of the study, fathers in the program group were likely to be working more ($p < .075$, 1-tailed Wilcoxon). No such change occurred in the comparison group. However, this result may be explained by regression to the mean and may be statistically isolated.

Finally, attainment of social workers' goals differed between the groups. These goals were often related to attachment (e.g., working on social support, relationship building, and developmental information, activities which involved enhancers of attachment and facilitating learned maternal sensitivity to the child's cues). Ninety-one percent of goals were attained for the program group, and only 76 percent for the comparison group. This difference does not reflect the difficulty of the goals, their importance, the areas the goals addressed, or the length of service delivered by the social workers in the two groups. All these confounding variables were recorded and compared. Several children in the comparison group had very long hospitalizations and the proportion of goals attained for these children did not improve over children with shorter hospitalizations. The average time goals were pursued did not differ between the groups, although this result reflected some outliers with extremely long hospitalizations in the comparison group. Given the intensity of the social work services for the program group, it was not surprising that there were many more social work goals for families in the program group.

The families in both groups were quite satisfied with social work services. This result was expected because both groups received high quality services. Means for degree of satisfaction were higher in the program group, but not significantly so. There was a trend for the program group to have used social work services in more of the core areas supported by the program ($p < .075$, 1-tailed Mann-Whitney).

Several outcome measures did not distinguish between the groups. First, the proximity/maintenance aspect of attachment, as measured by calls and visits to the hospital, did not differ between the groups, probably because the data were recorded inconsistently. Second, important

aspects of parenting did not change over time. Mothers' attitude toward the maternal role, social workers' ratings of parenting and of maternal autonomy were generally good or neutral to start with and remained so. Third, parent/child interaction, another aspect of attachment and a measure of the amount of learned sensitivity to the child's cues, also was similar in the two groups. Initially 28 percent of parent/child interactions were below normal, in part because of the children's medical status. About three quarters of the sample improved their interactions over time; improvement came from both the child's and the parent's contributions to the interactions. Fifth, most general life circumstances, potential enhancers or barriers to attachment because of their relationship to social support and socioeconomic background, did not change as a result of the program. Generally, mothers' relationships with the children's fathers and with the rest of their families, income, people living in the household, mothers' marital status, mothers' employment and enrollment in school, support mothers received, and fathers' attention to children remained the same after the initial interview.

There was also no difference between the groups in their ability to view their children as separate from themselves and capacity to form attachments, as described in their paragraphs. Over time, mothers viewed their children as increasingly separate from themselves ($p < .05$, 1-tailed Wilcoxon).

Finally, cognitive, motor, health, and child welfare outcomes were also unrelated to program effects. Bayley cognitive and motor scores reflected the incoming differences between the groups. The program group's scores were well below average, while the comparison group's were only slightly below the mean on average. The greater number of rehospitalizations and rehospitalization days in the program, as compared to the comparison group, again most likely reflects the greater prematurity of the program group children. Referrals to CPS were unusual in both groups and not very different. By the end of the study, no child was living in a nursing home or with relatives.

Summary and Discussion

These data indicate the program was successful in several ways. The program was clearly serving families with multiple risks for poor parenting, poor child outcomes, CPS involvement, and stays in the hospital past medical need. The data indicate that a relatively inexpensive program whose costs primarily involve social worker salaries and supervision can be effective in changing some of these risks.

The program was well liked by mothers and apparently lead them to use the core services offered. Various maternal affects (i.e., depression, overall anxiety, and parental stress) which are known to be related to poor child outcomes as well as to child abuse and neglect (Alpern & Lyons-Ruth, 1993; Radke-Yarrow et al., 1995; Radke-Yarrow & Zahn-Waxler, 1990; Field, 1992; Abidin, 1995) were reduced. High levels of worry about separation from their child were reduced, as well. It is often theorized that the results of these maternal affects are worsened by additional risks, such as children's illness, that occurred in this population (e.g., Teti, Gelfand, & Pompa, 1990). Mothers also gained developmental and medical understanding about their children's needs and began actively to participate in learning more about their children; these outcomes are likely to result in better parenting and improved developmental outcomes. Furthermore, there was some suggestion the program might be associated with increased paternal employment thereby increasing family support and self sufficiency. Lastly, the program facilitated attainment of the social worker's goals for the family. This outcome appears to reflect the intensity of services offered the families and the kinds of services delivered compared to traditional hospital social work.

The effects of the program appear to be very robust, because several factors mitigated against obtaining any significant program effects. The comparison group received some treatment over and above normal social work practice, and consequently we were comparing two levels of treatment rather than treatment versus no treatment. Additionally, the numbers of families studied

was small, so only the largest effects would be statistically significant. Note that comparable sample sizes are usual in studies of infants with these medical problems (Goetze, Immel, Escobar, & Gillette, 1993). Finally, the comparison group turned out to be more advantaged at the outset, lessening the chance that we could find differences between the groups.

It is not surprising that infant outcomes (Bayley scores) were unrelated to the program. A number of studies have suggested that the developmental effect may not appear until the children are 36 months old (e.g., Goetze et al., 1993; Boyce, Smith, Immel, Casto, & Escobar, 1993; Katz, Hussey-Gardner, & Baker, 1989; Zahr, 1994; Friedman & Sigman, 1992), and severe neurological and medical risks in neonates are the most important contributors to later developmental outcome although family variables also contribute (e.g., Thompson et al., 1994; Lobato, Watson, Coll, & Vohr, 1995).

Several aspects of our program are already known to be effective with disadvantaged/at-risk families and premature or neonatally comprised infants, although most other studies do not include as many children with as severe medical problems. Specifically, the home visiting component of the program, its targeting of new parents and intensiveness are all characteristics that have been documented as effective intervention techniques for prevention of child abuse and neglect, enhancement of child outcomes, and improvement of family/maternal outcomes (MacMillan et al., 1993; Daro & McCurdy, 1994; Scannapieco, 1994; Zahr, 1994; Wolfe, Reppucci, & Hart, 1995; Lucille Packard Foundation, 1993; Meisels & Shonkoff, 1990). While various studies suggest effective interventions take place over an extended period of time, some literature concludes that the intensity of service may be a better predictor of outcome than duration or service structure in preventing child abuse or neglect (Daro & McCurdy, 1994). “Low risk” and well as “high risk” families benefit from family-centered home-based programs, which generally have the effect of improving family functioning and preventing the placement of children (Scannapieco, 1994). Professionally trained staff who use more comprehensive service models such as ours are also cited as more likely to be effective (Lucille Packard Foundation,

1993). Nonetheless, a recent review of NICU programs showed few family services are given during the transition from the hospital to home, and even fewer services are offered after the infant returns home (Cardinal & Shum, 1993).

Some of our more specific results have also been found by other researchers. Depression and maternal stress can be reduced when there is family-based intervention in the NICU and during the transition to home (e.g., Meyer et al., 1994; Katz, Hussey-Gardner, & Baker, 1989). In addition, parents' knowledge about child development has been improved by home visiting programs that target new parents (Wolfe, Reppucci, & Hart, 1995).

Data on the core aspects of attachment addressed above yielded a picture of mothers who, for the most part, were slowly developing attachments to their infants despite the children's severe medical problems. A minority of the families, however, seemed to be experiencing trouble with this attachment.

In some instances, the program was able to enhance the chance that secure maternal attachment would develop. Thus, barriers to attachment such as negative parental mood and parental stress were reduced. Possibly fathers' financial support increased, a potential enhancer of attachment. Sensitivity of mothers to their child's cues was increased by learning about the child's special needs. Undue worry about separation, a sign that the relationship might not be able to withstand the long separation, was alleviated. Attainment of the social worker's goals (including goals related to the aspects of attachment discussed) was facilitated. Likewise, studies of caregiver-focused intervention in a home-visiting format frequently show positive effects on the relationship between parent and premature infant (Meisels & Shonkoff, 1990).

As a whole, the mothers' attachments to their infants had the following characteristics, which are discussed in terms of Ainsworth's six criteria critical to attachment. Specificity/selectivity in the relationship was present while the children were still in the hospital and under two months old.

Selectivity appears to increase as mothers get to know their babies. Duration of the relationship was also a feature of these early affiliations; mothers had intense anxious feelings about separation from their ill children.

There is indirect evidence that mothers' relationships to the children also reflected adult maturity levels, as opposed to maturity levels of infants. Mothers were able to tolerate separation from their hospitalized infants. Mothers at the bedside responded with more sensitivity to the children's distress than to nondistress cues, showing that mothers were concerned about distress. The mothers' relationships with their children also had affective implications. There was a strong reaction to being separated from the child. This anxiety abated by the end of the program for families who received services.

Most mothers also engaged in proximity/maintenance behaviors vis-à-vis their infants. On average during the hospitalizations, they had contact with their child by telephoning or visiting over once a day. A small number of families had very limited contact and were at significant risk for abandonment. Most mothers also worked to maintain a bridge in other ways between themselves and their infants in the hospital when parent and child could not be together. Mothers did this by bringing home mementos of the baby, leaving toys/clothes/pictures for the baby, and instructing the nurse on things to do with the baby when they were not there. On average, mothers were rated as engaging in moderate to high amounts of this bridging behavior during the child's hospitalization.

The development of the relationship of the mothers to their infants was also characterized by learning over time. Mothers became increasingly knowledgeable about prematurity and technology-dependence with time, especially in the program group. Learning about these issues occurred in most families, but families may need help with these topics. Improvement in the quality of the parent/child interaction over time also indicated learning within the relationship in most families. During their initial interactions with their children in the hospital, mothers showed

only moderate sensitivity to the babies' cues during times without distress, regardless of mothers' skills in sensitivity to cues. Mothers' sensitivity to concrete tasks such as child care and medical care was somewhat better.

Skills in parenting neonates and opportunities for acquaintance to develop between mother and child are factors that can enhance knowledge about the relationship. Distance from the hospital did not seem to be detrimental to opportunities for interaction. Average initial maternal skills in sensitivity to cues were moderately good; parents were initially more proficient in skills of medical and child care than general behavioral sensitivity. Most parents could benefit from some support in developing skills of sensitivity to general behavioral cues of their infants. By the time children were home and able to interact more normally with their parents, parents sensitivity to their cues was generally high.

Mothers' incoming capacities to form attachments with their children suggested significant risks for attachment relationships. A number of mothers were focused on their own needs and lacked understanding of their infants as separate persons. This understanding grew with time, but never reached very high levels for most mothers.

Several other parental characteristics and circumstances, in addition to the child's severe medical conditions, contributed to the array of factors likely to hinder the mothers' attachment to their children. The parents had high levels of parental stress, anxiety, and depression. Many of them lacked social support and were of low socioeconomic status.

Conclusion

This study found short-term encouraging results from an intensive family preservation program for children who had been chronically dependent on technology while in the NICU. These results indicate improvement in family functioning immediately after intervention ended at the point the children were medically stabilized in the community.

However, caring at home for children who are chronically medically fragile leads to high levels of psychological distress for their parents (Patterson & Leonard, 1994). Mothers often experience decreases in physical health (Patterson, Leonard, & Titus, 1992). Families are coping but at a price, with more severe psychosocial impact on the family associated with the severity of the child's condition (Patterson, Leonard, & Titus, 1992). Some studies suggest that parent coping may decline over time, so there is concern for the long-term impact on families (Patterson & Leonard, 1994).

It was remarkable, therefore, to see these families managing to support their children and keeping them in the community. Because of the degree of risk, however, it is likely that many of these families will need periodic support or continuing help after the program is over. Unfortunately, surveys show that few resources exist for these families (Office of Maternal and Child Health, 1995).

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**WHAT MAKES A PROGRAM WORK?
THE EFFECT OF LOCATION, COMMUNITY RELATIONSHIPS, MANAGEMENT
STRUCTURES, AND ORGANIZATIONAL COMMITMENTS ON PROGRAM
SUCCESS**

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Introduction

This chapter presents a comparison of two distinct Abandoned Infants Assistance (AIA) programs located in the metropolitan New York City area.¹ One program, which is no longer in operation, was located within a large, urban public hospital. This hospital-based (HB) program primarily provided referrals and assistance with obtaining services versus directly providing an extensive array of program-specific services. The other program, which took over the grant from the HB program and is currently in its second year of operation, is a component of a well-established community-based organization. Using a traditional case management approach, this community-based (CB) AIA program focuses more on combining direct services with a comprehensive referral system.

This chapter is based on our process of evaluating these two programs. It includes a comparative discussion of the two programs with consideration of the following issues: program models, administrative structures, agency reputation, organizational commitment to the evaluation, access to client data, human resources, style of service delivery, outreach and referrals, access to services, and the potential advantages of each model.

Though we draw a distinction between the two programs based on their setting (i.e., community-based vs. hospital-based), we acknowledge that not all of the differences in the two programs can

¹ Because one program is still being evaluated and the outcomes are not yet fully known, we are refraining from identifying either program by name at this time.

or should be solely attributed to this distinction. At the very least, the community-based program has had the advantage of learning from the experiences of the hospital-based program that preceded it. Some, though not all, of the other distinguishing factors are discussed in this chapter.

Program Models

In general, both programs shared similar core service program components. As designed, each program was to include the following core elements: aggressive outreach and education on prenatal care, parenting, and risks for mother-infant separation to women of childbearing age residing in the target communities; risk assessments during the perinatal period to identify women and infants at risk for separation; assessment of service needs; and, given the risks associated with infant abandonment, each program was to provide assistance and/or referrals for a variety of interventions including housing assistance, public assistance, parenting support and education, respite care, daycare, as well as prenatal substance abuse counseling and referral to drug treatment programs. A focus on the target children was to include screening, tracking, and referral to early intervention services as well as the assurance that medically fragile children would be placed in a setting where medical services and necessary apparatus were available to them. Both programs approached these goals through a case management model of assessment and service delivery. Described in more detail in a subsequent section, the fulfillment of these program goals and their methods of service delivery differed significantly.

Administrative Structures

The character of any program can in some ways be predicted by its place within a larger administrative context. This was definitely the case with regard to both of these AIA programs. Set within very different organizational contexts, each program struggled to develop an identity and purpose that would allow it to meet its goals, yet be accepted as part of the organization in which it was housed.

The hospital-based (HB) AIA program was set within a very large, municipal hospital system with a formal, multi-layer bureaucratic structure. In the hierarchy, the AIA program was far removed from the administrative level. In fact, it was, by comparison to other hospital programs and departments, a small and not very visible nor clearly defined program which was often obscured by the overarching hospital system. The multiple layers of the hospital bureaucracy often resulted in some confusion over lines of communication and authority, as well as the duplication of some services by various hospital departments and the AIA program.

Adding to the complexity of the administration of this program, two co-directors were hired at the urging of the state oversight agency. One was a masters-level social worker; the other was a registered public health nurse. Both had long histories in the parent hospital system. The initial intent of the co-directorship centered around the social service needs and physical health risks of the clients and the risk for their children. It was felt that outreach to the relevant agencies and to the community might benefit from the coordination of the two disciplines.

In theory, this model was plausible; in reality, it posed problems for the program. The practice of sharing responsibilities was reported by staff to be at times disruptive to the cohesion and continuity of the program. This stemmed primarily from the directors' very different professional stances and, in particular, their perspectives on the criteria for program admission. For any program to have a chance to run smoothly, at the very least, leadership must have a shared view of purpose and be able to transmit that to their staff in a consistent and meaningful manner. This proved problematic for the HB program and, in our view, rested heavily on the conflictual nature of the co-directorship model.

The community-based (CB) AIA program, on the other hand, exists within a much smaller, but no less established, organization. A formal hierarchy governs the agency, however, lines of communication appear to be clear and direct. This clarity of communication also extends to the program level under the singular direction of a masters-level social worker. Though internal staffing problems did hinder some of the initial efforts of the program, communication among staff

and role expectations have remained strong and consistent. Furthermore, with an executive level active in each program component's functions, duplication of services appears to be minimized.

For various reasons, not completely understood as yet, the two programs have responded to change very differently. The CB program has been much more flexible and willing to adjust the program design, services, and staffing to the changing needs of the community and the clients. An example of this flexibility was the establishment of a rap group in response to the community's need for acknowledgement and support of grandparents with primary care responsibilities for children. The HB program, on the other hand, seemed to resist change and reacted as though changing services or the program design would signify weakness or fault. As a result, the program did not adapt quickly nor effectively to changes in client needs or program redefinition. From the outset, it appears that the CB program's administrative structure was more receptive to the addition and incorporation of the AIA program component, which although consistent with the overall goals of the organization, required flexibility and an adaptive quality that the HB program's host hospital was less able to accommodate. The latter may have been partly due to the long and complex history of the parent hospital system which is discussed in the next section.

Agency Reputation

Although some program administrators would like to believe that "if we build it they will come," even those clients most in need of services must often be convinced that they should take advantage of the services that a particular program can offer them. The reputation that a program has in the community often influences clients' decisions to come to a program. Such was the case with both the HB and CB AIA programs discussed in this chapter.

In general, the target communities served by both these AIA programs are relatively service-rich, with established social service systems. The CB program has had the advantage in this arena because its umbrella organization has a 20-year history of service delivery, is well-established in the community, and has a positive reputation among residents as well as service providers. Much of this community acceptance is attributable to the organization's longstanding commitment to the

community, most notably exemplified by its employment of community residents and the purchase of goods and services from local suppliers. The organization has worked hard to keep its public relations profile high, both for the overall agency and for the AIA program. This effort will mostly likely have a long term payoff. Although the volume of referrals (both agency and self-initiated) has not yet been overwhelming, it is expected to have a significant impact on the community in terms of service penetration and community need fulfillment.

The HB program, on the other hand, faced many obstacles. It was a small, new program with relatively inexperienced direct service workers trying to carve out a niche in a large and established service system. Surely, one can make a case for developing and implementing a program in an existing hospital structure. The availability of resources, a ripe environment for referrals, and the familiarity of the structure within the community are potential strong advantages, however, there are also risks to this approach. In this instance, the host hospital was large and had a pre-existing negative reputation in the surrounding community regarding the perceived quality of services, staff, and facilities. For some individuals, the juxtaposition of the AIA program to the host hospital may have been a negative factor, while the physical infrastructure of the sprawling hospital campus may have been daunting to others.

It is possible that a program might be more approachable and accessible to clients if not housed in a large and overwhelming institution, particularly one already suffering from negative community perceptions. This appeared to be the case for the HB program, which was seemingly unable to overcome the negative image that the hospital had in the community with regard to the complex nature of the organization, the difficulty that many clients had in negotiating the system, and the community's perception, whether accurate or not, of the quality of care and conditions in the hospital. This, coupled with lack of a well-defined and effective outreach strategy, resulted in fewer client contacts than initially estimated. This is discussed further in a subsequent section.

Organizational Commitment to the Evaluation

As with many funding initiatives, each AIA program is required to have a third-party evaluator. Evaluation can be viewed by the program as an objective, constructive method to ensure that clients' needs are being met or, at the opposite end of the spectrum, as an intrusive process threatening the continuation of funding. We experienced the latter with the HB program. Much of what we proposed was resisted by the hospital administration and program directors. The reasons for this resistance remain somewhat unclear, however this reaction made implementation of the evaluation design difficult. Successes in completing the various components of the evaluation became a function of enticements, gentle coercion, and the willingness of some staff to participate in and facilitate the process. In some instances the administrative project officer had to intervene to assure compliance.

The CB program has leaned more toward the other end of the spectrum, primarily as a result of the commitment and intervention of the agency's executive staff. Though we have had to deal with some difficulties in the evaluation process, the organization seems to be committed to the evaluation and eager to utilize the feedback we provide.

A key component to the completion of a comprehensive and accurate evaluation of a program is access to client data. In the case of AIA programs, access to medical data is extremely important. It was in this area that the HB program could offer a more complete picture of the client. Due to the fact that most clients had been referred via the inpatient side of the hospital or had been at some time a patient of the hospital's clinic system, complete medical records were readily available to the staff and evaluators. Additionally, extensive preliminary efforts were made to develop an intake instrument, database system, and data transfer procedures, that would meet the needs of both the program and the evaluators without duplicating paperwork demands on staff. This, coupled with the access to medical records, provided a very complete picture of the client. Very little reliance had to be placed on clients' self-reporting of their substance involvement, medical status, or service history.

At the CB program, staff and evaluators have limited access to medical records; much of the information must be reconstructed from client self-reports to be entered into the client database. The limitations of this access are uncertain at this time, although it is clear that both staff and evaluators must be cautious in their reliance on medical information provided by the client. Efforts to create referral and assessment forms which meet the dual needs of the program and the evaluation also occurred at the CB program. When we began our relationship with the organization, it had recently unveiled its new comprehensive automated management information system. Rather than adapting our existing database system used at the HB program, the CB organization offered to create a database component for the AIA program which could be appended to the larger system. The rationale underlying this approach was sound in terms of practicality and efficiency. In practice, this has proven to be problematic primarily due to the differences in data needs--program administrators need management information and the evaluators need statistical data.

Human Resources

There were distinct differences in staff and staffing models between the two programs. Both programs experienced various difficulties with staff which may have affected program outcomes. The staffing model at the HB program was small and concentrated: five caseworkers, one substance abuse counselor, and two co-directors. Although there were discussions about involving peer counselors, no peer counselors or volunteers were incorporated into the staffing model. For most of the five caseworkers, this was their first experience working in human services and their first time working directly with clients. They had little, if any, formal training and none had completed college. Though they were well-intentioned and highly motivated, they needed *and wanted* ongoing training. They received some clinical supervision (mostly a cursory review of charts and a discussion of problematic cases with the co-directors) and sporadic in-service training despite the rich variety of resources within the hospital and the free training curriculum offered through the AIA Resource Center. As a result, the “counseling” clients received was more like chatting with a friend--which can be beneficial but certainly is not clinical. Not only did this fall short of the original goals of the program, but the program remained static;

there was little encouragement from leadership to enhance knowledge and skills. Many of the successes in engaging clients can be attributed to the efforts, commitment, and initiative by a few key individual staff members.

Despite some significant personnel issues which lingered throughout the first year of implementation, the staffing model of the CB program has some assets which the HB program did not have. It is a larger, interdisciplinary set of professional and paraprofessional staff: one M.S.W. program director, one masters-level clinical supervisor, two case managers, one public health nurse trainer, one substance abuse counselor, and, to date, seven part-time grandparent mentors.² Professional staff across disciplines have college degrees and came to the program with more experience working with clients in the human services. (The average number of years working in the human services among direct care professionals is two). Despite the range and combination of experiences, the program director recognizes the value of ongoing training to remain abreast of developments in an ever-changing environment.³ Program staff are offered regular in-service training by professionals from various community agencies, and they have received consultation and a training session from the AIA Resource Center.

The two types of programs differed in their amount of flexibility in dealing with personnel issues. Though we are unable to confirm the salaries of workers, anecdotal information (and organization theory) tells us that the HB staff earned higher wages than the CB staff. The total budgets for the two programs were comparable, however, more of the HB program's budget was devoted to program administrative costs as it had to meet the monetary obligations of the hospital salary and benefits structure. Personnel costs were further increased by the decision to support two directors, both of whom had considerable work experience (in and out of the hospital) and had grown through the salary tiers of the hospital system.

² The recruitment of volunteer mentors, as originally designed, has been unsuccessful; the efforts are continuing.

³ Trainings have also been utilized to address some internal issues among staff.

As a non-profit organization, the CB program seeks to keep administrative and personnel costs low relative to program operation costs. Working within a less rigidly structured personnel system, the CB program is not obligated to a formal, tiered salary system. Consequently, it strives to devote a higher proportion of its budget to program costs with the intent to shift the benefit to service recipients. The impact of this on staff recruitment, retention, and morale is worthy of further exploration.

The two programs differ in their parent organization's commitment to staff. At the HB program, there were two influences working parallel. On the one hand, working within the protections of a large bureaucratic hospital system, direct care staff could concentrate on performing their duties rather than worrying too much about from where their next paycheck might come. On the other hand, this seemed to have led to a sense of security knowing that if their program did not continue, some of the longer term hospital employees could transfer into backup positions within the hospital system or the administrative corporation.

Because there is no job protection at the CB program, there may be a potential stronger commitment to achieving program goals and demonstrating success in order to secure continuing funding and a job future. An illustration of this difference is in the two programs' anticipation of termination: early in their second year, the CB program began seeking continuation funding beyond the "guaranteed" federal funding through the AIA Act, whereas the HB program made little effort to secure additional funding, presumably relying on the hospital to protect their careers.⁴

Style of Service Delivery

Consistent with other issues described in this chapter, there were marked differences in the style of service delivery of the two programs. Each was in line with the overall approach of its parent agency. Following the traditional medical model of the host hospital, the HB program was

⁴ Some of this difference might also be attributable to the circumstances of termination: funding to the HB program ended due to programmatic issues; the CB program is facing the potential end of funding based on actions at the federal level.

primarily office-based, with clients expected to come to the hospital campus for “appointments” and staff not initiating an inordinate amount of community contact. This occurred despite a program description that highlighted what should have been an aggressive outreach approach. It appears, however, that this outreach was indirectly discouraged both by the organization's overall approach as a medical facility, as well as an implemented service delivery strategy that was heavily reliant on referrals from hospital clinics and the inpatient maternity unit.

The CB program also utilizes a model consistent with the umbrella organization's approach. Unlike the HB model, outreach and community involvement are integral to the program. This approach seems not only to be encouraged but rewarded, while an office-based approach is discouraged.⁵

Interestingly, despite the office-based nature of the HB program, its efforts were directed more at case management and the referral of clients to community agencies and less on direct service delivery or “counseling”. The CB program provides more direct services, including education, support groups, and counseling. The difference is that the CB program attempts to provide some of these services out of the office setting (e.g., at clients' homes).

Outreach and Referrals

Whether self-contained or set within a pre-existing institution, new programs must find the most appropriate and effective manner to introduce themselves to the community. It is the responsibility of all staff, both managerial staff as well as line staff, to develop communication between their program and the community. In direct service programs, administrators offer individuals with self-initiative, familiarity with the community, and established networks of contacts. A program, however, should have a viable plan other than relying on the informal relationships and individual efforts of workers to secure resources.

⁵ It should be noted that the CB program had the benefit of feedback from the funders about the perceived shortcomings of the previous HB program and may have adapted its model to respond accordingly.

Stark differences emerge in this area between the two programs. HB workers had to rely heavily on their own individual efforts and personal contacts to establish professional relationships and to obtain concrete items such as clothes, cribs, and baby supplies. These contacts were then informally shared among the staff and eventually integrated into the overall program. CB workers, on the other hand, have programmatic support for such efforts--relationships between the AIA program and other agencies are established (or already exist with the umbrella organization) and formalized by the program director. As a small indistinct program, the HB program did not receive this level of commitment from the large hospital administration, nor did workers feel it from their program directors.

The differences in referral sources and program models between the hospital-based and the community-based AIA programs account for some of the differences in each program's approach to outreach. For example, the hospital-based program received the majority of referrals from departments within the hospital system. That the flow of clients from these sources was judged adequate by the program directors reduced their perceived need for aggressive community outreach.⁶ Even within the hospital system itself, workers expressed frustration over the lack of familiarity of hospital staff with their program. Internal and external outreach, as a specific program objective, was not clearly and adequately defined and therefore was not fully implemented at this program.

In contrast, the outreach targets of the CB AIA program were clearly articulated in the original program design. And, despite the fact that many referrals were expected to come from programs within the umbrella organization, the AIA program has been creative and assertive in its outreach activities. For example, the director and case worker personally visited many area agencies, (e.g., homeless shelters, substance abuse treatment facilities, teen programs, and schools) posted flyers on street corners and in store windows, and distributed brochures at food pantries, W.I.C. offices, and check cashing offices. Additionally, more non-health related facilities have been contacted for

⁶ The fact that the program served only 20 percent of its expected capacity raises some interesting questions about the decisions being made about the flow of referrals and subsequent outreach efforts. It may also indicate the level of difficulty this program faced in overcoming the hospital's reputation in its outreach efforts to the community.

referrals than was the case for the HB program. However, adjustments had to be made to counter some side effects of initial misdirected outreach efforts (i.e., outreach efforts to clients with needs beyond the scope of the program's services).

The location of the programs may have had a differential effect on workers' perspectives on outreach. For workers in the CB program, home visits, outreach, and visibility in the community is a "given" component of their duties and an integral part of the overall set of services. In fact, the program currently has seven grandparent mentors whose primary job function is to make contact with clients and potential clients in the community. Workers of the HB program saw outreach, home visits, and community-based work as an "extra" job duty and one they did not necessarily relish. As we have already pointed out, it was a much more office-oriented program. Though out-of-office contacts were made and workers escorted clients to appointments with other agencies, workers preferred to have clients make appointments to come in for "counseling". This was probably due to the medical orientation of the program. Given the population and the difficulty many clients faced in going into the hospital setting, this was not the most effective nor realistic mode of client engagement and retention. Finally, the orientation of the two programs also played into the targets for outreach. In terms of identifying referral sources, the HB program focussed primarily on health-related facilities whereas the CB program casts a broader net across the social service system.

Access to Services

The HB program had relatively easy access to health-related services within the host hospital. In one sense, this easy access, at times, may have indirectly discouraged workers from seeking alternatives external to the hospital system, including non-health related services. In another sense, this was clearly a benefit. Program staff could utilize the range of services available, and had priority access over outside agencies, as necessary. For example, on behalf of their clients, staff could refer directly to the inpatient detox unit, the health clinic for women's and children's health check-ups and immunizations, the on-site Women Infants and Children (WIC) office, and

lab work for drug toxicologies and blood work. Additionally, caseworkers could ensure that clients got to services by escorting them just minutes from the AIA program.

The CB program does not have *a priori* access to such hospital services, as in the case of the HB program. Access to such services (though possible) is complicated by the need for establishing formal or informal agreements and referral procedures. Given its program design and physical location, the CB program has concentrated its efforts on making arrangements with community agencies that are in closer proximity to its home office and clients.

Potential Advantages of Each Model

As we have discussed, the AIA programs described in this chapter experienced both obstacles and successes as each program model was implemented. Stepping back from the specifics of each AIA program, both organizational models offer potential distinct advantages. A few of these are outlined below. These advantages, though presented as contrasts, are neither exhaustive nor mutually exclusive.

Hospital-Based Models. The HB model offers several benefits to an AIA program, planners, implementers, and evaluators. First, given the vast array of medical information that is needed on clients of AIA programs, the hospital data system offers one, self-contained medical record for each client. Regardless of when, how often, or where in the hospital a client accesses the program, a single medical record exists (at least in theory). This reduces the need for searching for information across various agencies, the duplication of (sometimes conflicting) data, and the reliance on client self-report of important and sensitive information. Furthermore, a program placed within and supported by the host hospital can enjoy *de facto* access to these readily-available data.

Second, clients and program staff often face difficulties in gaining admission into the various programs they require. The HB program obviates some of that problem in that, since the client is already a “hospital patient”, referrals to other programs within the host hospital are facilitated. A

related point is that this self-contained nature not only can enhance referrals out of the program -- particularly important for the referral-focused HB AIA program discussed in this chapter--but also referrals to the program from other programs or departments within the hospital setting. However, other departments within the agency must be educated about the program.

Third, clients in these programs often need to access the services of a wide array of professionals beyond the scope of the AIA program. This also holds true for the direct service staff who can draw upon the expertise of professionals throughout the hospital through in-service trainings and information exchange meetings. The hospital offers this breadth of professionals typically beyond those of a community-based program.

In addition to this array of professionals, the technology that accompanies them is also available to staff and clients. This may include existing technologies, such as substance toxicologies and blood work, as well as access to new or experimental treatments that would be unavailable (or, at least, not as easily accessible) outside of the hospital system. This is particularly important for those clients whose medical conditions require not only prompt but aggressive treatment, such as the treatment needed for clients with HIV/AIDS-related conditions.

Community-Based Models. The CB model also offers several distinct advantages in implementing an AIA program and related evaluation activities. First, a well-developed umbrella CB organization should have established strong ties to the community. Most, if not all, of these programs arise from the community's identification of need. Often, initial efforts come from either an existing CB organization or a related service type organization such as a local church or community center. This is particularly important for programs that rely heavily on identifying and accessing clients who might not come to the system through traditional means. For example, in some communities, alternatives to mainstream health care exist within the community. A CB organization, which is trusted by those in the area, will be much more likely to be accessed by clients who are otherwise distrustful of conventional programs.

Second, and related to the first point, a CB program is likely to have a better understanding of community needs since it “lives” in the neighborhood and those working for it are better able to see what is going on in the community. In addition, this understanding of community need allows the program to be more flexible in its approach and to adapt to the changing needs of the community as necessary.

Finally, there are advantages in CB agencies which have a smaller, more direct administrative structure. Decision-making within the overall organization and the program can occur more efficiently, with modifications to the service delivery system being implemented in a timely fashion.

As stated at the beginning of this section, the advantages of each model, as presented, should not be interpreted to be either exhaustive nor mutually exclusive. For example, a hospital-based program can generate a community presence, and a community-based program can access the resources of a hospital. And, to varying degrees, each of the AIA programs discussed in this chapter has tried to integrate some of the advantages of the other model.

Conclusion

In this chapter, we have used our experiences as evaluators to draw out some of the fundamental organizational differences--in terms of both advantages and obstacles--between a hospital-based AIA program and a community-based AIA program. Clearly, not all of the differences between these two programs can or should be solely attributed to their service settings, nor should they be generalized to other AIA programs in similar settings.

Each program has faced its own set of issues and, in general, developed strategies to address each with varying degrees of effectiveness. Some successes can be attributed to the creative efforts of individual staff members--both administrative and direct service workers. Other achievements

could not have been accomplished without the support and commitment from the host organizations.

Almost regardless of these individual factors, a successful program must be clear at the outset in its design, target population, program goals and objectives, and specific service components. And, it must be willing and able to adjust any or all of these to continue to meet the needs of the community it intends to serve. Furthermore, these program elements must be clearly and consistently communicated to the direct service workers who not only represent the organization, but must fulfill the goals of the program as they serve clients in the community and should be involved in making these decisions.

Finally, there are benefits to be found in any organizational setting. A successful program will be guided by a leader(s) who can identify and then utilize these benefits to the advantage of the individual program and the clients it aims to serve.

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Chapter 1

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Chapter 2

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Chapter 3 **Developmental Outcomes in Infants at Risk**

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Chapter 5

Evaluation of Project Lagniappe, Children's Hospital of New Orleans

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Chapter 6

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Chapter 7

Progress Toward Permanency for HIV-Affected and Substance-Exposed Children in the Child Welfare System: Illinois' Project "First Love" Community-Based Hospital and Foster Care Programs

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Chapter 8

Helping Families Make the Transition from Hospital to Home Care: Evaluation of a Program for Families of Technology-Dependent Children

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Chapter 9

What Makes a Program Work? The Effect of Location, Community Relationships, Management Structures, and Organizational Commitments on Program Success

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